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Elimination of racism, racial discrimination, xenophobia and related intolerance: comprehensive implementation of and follow-up to the Durban Declaration and Programme of Action

Combating racism, racial discrimination, xenophobia and related intolerance and the comprehensive implementation of the follow-up to the Durban Declaration and Programme of Action

Note by the Secretary-General

The Secretary-General has the honour to transmit to members of the General Assembly the interim report submitted by Githu Muigai, Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance, pursuant to Assembly resolution 63/242.

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Interim report of the Special Rapporteur on contemporary forms of racism, racial discrimination, xenophobia and related intolerance

Summary

The present report to the General Assembly is submitted pursuant to Assembly resolution 63/242 on global efforts for the total elimination of racism, racial discrimination, xenophobia and related intolerance and the comprehensive implementation of and follow-up to the Durban Declaration and Programme of Action.

In chapter II of the report, the Special Rapporteur makes reference to the Durban Review Conference, which was held from 20 to 24 April 2009, in Geneva. In chapter III, the Special Rapporteur describes the activities carried out in the framework of his mandate. As such, it refers to country visits — including by the former mandate holder — and press releases. Chapter III also refers to thematic issues addressed by the Special Rapporteur through his participation in conferences, seminars and other meetings since his last report to the General Assembly (A/63/339). Those issues include incitement to racial or religious hatred, poverty, genocide, and discrimination based on descent. Finally, the Special Rapporteur presents a number of conclusions and recommendations relating to the Durban process and to the above-mentioned thematic issues.

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I. Introduction

1. The mandate of the Special Rapporteur on racism, racial discrimination, xenophobia and related intolerance was created by the Commission on Human Rights in its resolution 1993/20 and further refined in its resolution 1994/64. In March 2008, the Human Rights Council reviewed, rationalized and improved the mandate. As a result, the Human Rights Council adopted resolution 7/34, which extended the mandate of the Special Rapporteur for a period of three years and set out the terms of reference in paragraphs 2 and 3 of the resolution.

2. The present report is submitted pursuant to General Assembly resolution 63/242 on global efforts for the total elimination of racism, racial discrimination, xenophobia and related intolerance and the comprehensive implementation of and follow-up to the Durban Declaration and Programme of Action.

3. Chapter II of the report is devoted to the Durban Review Conference, held from 20 to 24 April 2009 in Geneva. Chapter III describes the activities carried out in the framework of the mandate. As such, it refers to country visits — including by the former mandate holder — and press releases. Chapter III also refers to thematic issues addressed by the Special Rapporteur through his participation in conferences, seminars and other meetings since his last report to the General Assembly (A/63/339). Those issues include freedom of expression and incitement to racial or religious hatred, poverty, genocide, as well as discrimination based on descent. Finally, the Special Rapporteur presents a number of conclusions and recommendations relating to the Durban process and to the above-mentioned thematic issues.

II. Durban Review Conference

4. The first year of appointment of the Special Rapporteur was obviously very much marked by the Durban Review process and the holding of the Durban Review Conference in April 2009. Consequently, the Special Rapporteur devoted a significant chapter to the Durban Review Conference in his annual report submitted to the eleventh session of the Human Rights Council (A/HRC/11/36). During the Durban Review process, he often stressed that the Review Conference constituted a unique opportunity to rebuild strong international consensus and mark the renewal of the international engagement in the struggle against racism. In that respect, he emphasized that the Durban Review Conference should be seen as the beginning of a new era of international mobilization in the fight against all forms of racism, rather than the culmination of the Durban Review process.

5. The Special Rapporteur was particularly pleased that the outcome document was adopted consensually by all participating States. While the Special Rapporteur regretted that 10 States had decided not to participate in the Review Conference, he recommended that those States publicly acknowledge their support to the outcome document.

6. On the question of freedom of expression and the fight against racism, which was key during the negotiations, the Special Rapporteur noted with satisfaction that the text agreed upon represents a landmark in the way the United Nations human rights system will in the future approach this issue. The Special Rapporteur welcomed the fact that the outcome document referred to the language of

international human rights standards contained in the International Covenant on Civil and Political Rights and in the International Convention on the Elimination of All Forms of Racial Discrimination.

7. Now that the outcome document of the Durban Review Conference has been adopted, the Special Rapporteur hopes that the momentum gained during the Durban Review process will retain its strength. He would like to strongly emphasize that pledges and commitments made in the outcome document be effectively implemented by all States, which retain the primary responsibility in this respect. Racism is still pervasive around the world and appropriate legislation, institutions and policies are more than ever necessary to fight against this scourge.

8. In the implementation of his mandate, the Special Rapporteur intends to use the outcome document of the Durban Review Conference as a blueprint and a theoretical framework for analysing issues relevant to his mandate during country visits, and in other regular activities. In this view, the Special Rapporteur submitted in his annual report to the Human Rights Council (ibid.) a table listing the action-oriented commitments made by States and some initial indicators to monitor performance to meet those commitments. He would like to recommend that States use similar tools in order to identify concrete measures and to establish a road map for the implementation of the outcome document of the Durban Review Conference.

III. Activities of the Special Rapporteur

A. Country visits

9. Country visits constitute an important opportunity for the Special Rapporteur "to gather, request, receive and exchange information and communications with all relevant sources, on all issues and alleged violations falling within the purview of his mandate, and to investigate and make concrete recommendations, to be implemented at the national, regional and international levels, with a view to preventing and eliminating all forms and manifestations of racism, racial discrimination, xenophobia and related intolerance", in accordance with the mandate entrusted to him by the Human Rights Council in resolution 7/34.

10. Following his appointment in August 2008, the Special Rapporteur sent formal requests to visit Bangladesh, the Plurinational State of Bolivia, Bosnia and Herzegovina, Germany, India, Israel, Malaysia, Mexico, Nepal, South Africa, the Sudan and the United Arab Emirates. The Special Rapporteur would like to acknowledge the letters of invitations extended to him by the Plurinational State of Bolivia and by Bosnia and Herzegovina. While he has not been able to honour these invitations yet, the Special Rapporteur hopes that he will be able to do so in the near future.

11. In the following paragraphs, the Special Rapporteur would like to inform the General Assembly of the visit carried out by the former mandate holder to the United States of America, of his first country visit carried out to Germany, and of his upcoming visit to the United Arab Emirates.

1. Mission to the United States of America by the former mandate holder

12. The former mandate holder visited the United States from 19 May to 6 June 2008 at the invitation of the Government. The current mandate holder submitted the report on the visit to the Human Rights Council at its eleventh session (A/HRC/11/36/Add.3).

13. The report highlighted the strong awareness and recognition at all levels of government and society regarding the challenges in the fight against racism in the United States. The former mandate holder commended the country for the comprehensive legal framework put in place since the adoption of the Civil Rights Act of 1964 and noted the important role played by the Supreme Court of the United States in the fight for civil rights. Finally, he also made reference to the vitality of civil society in the country, playing a key role in holding governments accountable to their obligations.

14. The report also focused on key areas of concern that need to be addressed in the future. The first set of challenges involves instances of direct discrimination and concrete racial bias, which is more pronounced with regard to law enforcement agencies. Particular reference was made in this respect to racial profiling, including in the fight against terrorism, and other aspects of the criminal and juvenile justice systems. Secondly, the report addressed cases of laws and policies that are prima facie non-discriminatory, but that have disparate effects for certain racial or ethnic groups, such as the practice of mandatory minimum sentences. Finally, the report described at length the overlap of poverty and race in the United States, which has a profound impact for minorities, particularly in areas such as education, housing and employment, creating a vicious cycle of marginalization and exclusion. This socio-economic marginalization of minorities has contributed to a slow process of de facto re-segregation in many areas of the society, directly challenging the goals of integration and equal opportunities.

15. To address these challenges, the former mandate holder made a number of recommendations to the authorities. These included the need to establish a bipartisan Commission to evaluate progress and failures in the fight against racism and the ongoing process of re-segregation; the reassessment of existing legislation for the identification of possible racial bias; and the enactment of comprehensive legislation prohibiting racial profiling.

2. Mission to Germany

16. The Special Rapporteur visited Germany from 22 June to 1 July 2009. He would like to express his sincere appreciation to the Government of Germany for its full openness and cooperation throughout the visit. A detailed report containing the observations and conclusions of the Special Rapporteur on the visit will be submitted to the Human Rights Council at its fourteenth session, in 2010.

17. In the press conference held in Berlin on 1 July 2009,[1] the Special Rapporteur recalled that the challenges faced by Germany were similar to those faced by many other European countries, and therefore Germany was a good measure of how Europe was doing in matters related to racism. He highlighted positive trends in

[1] The full text of the press release is available online from http://www2.ohchr.org/english/issues/racism/rapporteur/docs/PRelease_end_mission010709.pdf.

German society and political institutions regarding issues of racism. In that regard, reference was made to the adoption of the General Equal Treatment Act in 2006 and to the establishment of the Federal Anti-Discrimination Agency. The Special Rapporteur also noted with appreciation that the authorities at the highest level recognized that Germany was today a country of immigration. This recognition reflected a commitment of the authorities to address underlying challenges stemming from migration.

18. The Special Rapporteur acknowledged that much had been achieved in the fight against racism in the past few years, but much remained to be done. He identified two critical areas which deserved immediate attention. First, he recommended a broadening of the understanding of racism. While the understanding of racism by the society at large had been equated to right-wing extremism, the Special Rapporteur underlined the necessity to approach the question of racism from the standpoint of structures and institutions that facilitate the integration of migrants in German society. Secondly, he referred to the strong form of federalism in Germany and to the challenges concerning the transformation of Federal laws and programmes into concrete actions at the local level. The Special Rapporteur emphasized the need to ensure that local governments had effective legal and institutional frameworks that responded to the many challenges of the problem of racism.

19. In addition to these core issues, the Special Rapporteur addressed the necessity to strengthen the institutional and legal framework to fight racism and to fight extremist right-wing groups and parties. He also raised the situation of specific communities and the situation of refugees and asylum-seekers which was referred to as a major concern. The question of education, housing, employment and political participation of persons with a migrant background or coming from minority ethnic or religious backgrounds was also considered by the Special Rapporteur as deserving particular attention by the Government. He strongly recommended that special measures be taken to ensure an adequate representation of persons with a migrant background in State institutions — particularly in the areas of employment, education and the creation of political opportunities, including in the civil service — in order to correct existing imbalances and to offer such persons adequate opportunities to make a lasting contribution to German society.

3. Forthcoming mission to the United Arab Emirates

20. The Special Rapporteur would like to thank the Government of the United Arab Emirates, who have agreed to invite the Special Rapporteur for a country visit from 5 to 9 October 2009. This visit will constitute the first visit of a special procedure mandate holder to the United Arab Emirates and the Special Rapporteur is very much looking forward to engage in a constructive dialogue with the authorities on all matters related to racism, racial discrimination, xenophobia and related intolerance.

B. Press releases

1. International Day for the Elimination of Racial Discrimination

21. On the occasion of the International Day for the Elimination of Racial Discrimination, on 21 March 2009, the Special Rapporteur released a press statement calling for full engagement in the Durban Review Process.

22. He reaffirmed the continued relevance of the fight against all forms of racism and stated that displays of intolerance abounded, from small gestures in interpersonal relations to large-scale violence targeting people of different skin colour or ethnicity. In times of global financial crisis, the Special Rapporteur warned against intolerance, which tended to become even more pronounced, fostering racial, ethnic and xenophobic tensions.

23. The Special Rapporteur emphasized that the time was ripe for a renewed international engagement against racism and that the Durban Declaration and Programme of Action remained the most comprehensive framework of international, regional and national actions needed to counter racism. A successful Review Conference would empower all stakeholders across the world, providing them with additional tools to be employed in their daily fight against racism. He therefore called upon States as well as civil society organizations to participate constructively in the negotiations leading to the Review Conference in April 2009 and to devise consensual solutions that could make a positive impact on people's lives.

2. Situation of Roma in Europe

24. On 20 November 2008, a press statement was released jointly with the United Nations Independent Expert on minority issues in order to express their grave concern over the recent rise in anti-Roma sentiment and violent incidents in several European countries. The two experts underlined that effective action was required to stem the growing tide of hostility, anti-Roma sentiment and violence across Europe. In this regard, they referred to the necessity to fully use the criminal justice system in order to protect targeted populations. Both experts also stressed that such actions revealed serious and deep-rooted problems of racism and discrimination against Roma at the heart of modern Europe, and had to be addressed in the most vigorous manner and through the rule of law. They recalled that Governments must strongly condemn such actions. Moreover they must be committed to finding ways to create safe environments for all by carefully monitoring and strengthening their own anti-racism activities, through leadership and public education, by swiftly denouncing hate speech and prosecuting the racist and violent actions of others in society.

25. Furthermore, the two mandate holders expressed the view that the policies and actions of numerous States had been, at best, inadequate to resolve intolerable conditions of poverty, marginalization and exclusion experienced by the Roma minority in Europe. Policies such as finger-printing of Roma, abuse by police, and racist statements by senior public officials had contributed to creating a climate in which societal discrimination and racism were sustained and enhanced. The growing number of such incidents required both a national and Europe-wide response and the experts stressed the need for the European Union to send a strong message, which must be acted upon by Member States. International law, European directives and national policies must be strongly enforced by national Governments and at the

level of local government where, according to the experts, the message of anti-racism was not getting through.

C. Thematic issues addressed by the Special Rapporteur through his participation in conferences, seminars and other meetings

1. Incitement to racial or religious hatred

26. Since his last report to the General Assembly (A/63/339), the question of incitement to racial or religious hatred has been raised by the Special Rapporteur through various reports and statements which are summarized below.

27. At the ninth session of the Human Rights Council, the Special Rapporteur submitted, pursuant to Council resolution 7/19, a report drafted by his predecessor on "the manifestations of defamation of religions and in particular on the serious implications of Islamophobia on the enjoyment of all rights" (A/HRC/9/12).

28. In the report, the analytical framework presented by the former mandate holder to the Human Rights Council in the past is summarized and updated. In particular, a clear call is made to Member States to shift the discussion in international forums from the idea of "defamation of religions" to the legal concept of "incitement to national, racial and religious hatred, hostility or violence", which is grounded in international legal instruments. In that regard, the report contains a detailed examination of the current normative framework on the question of incitement to hatred, showing that protection against this kind of hate speech has been crafted at length in international law, including in articles 19 and 20 of the International Covenant on Civil and Political Rights, and in article 4 of the International Convention on the Elimination of All Forms of Racial Discrimination.

29. On 12 November 2008, the Special Rapporteur participated in a conference on "Human rights in culturally diverse societies: challenges and perspectives", organized by the Council of Europe. On that occasion, he addressed the issue of "hate speech", which is used as a convenient short term to describe the legal notion of advocacy of national, racial or religious hatred that constitutes incitement to discrimination, hostility or violence, as contained in article 20 of the International Covenant on Civil and Political Rights.

30. In particular, the Special Rapporteur referred to the expert seminar on the links between articles 19 and 20 of the International Covenant on Civil and Political Rights, organized by the Office of the United Nations High Commissioner for Human Rights (OHCHR), in October 2008. The seminar brought together a number of academics and experts, who identified the key challenges and put forward some recommendations. When applying articles 19 and 20 of the Covenant, they pointed to the need of a case-by-case approach, therefore taking into account, for instance, the history of violence or persecution against a particular ethnic or racial group, which can be a meaningful indicator of their vulnerability. Further, the experts were of the view that when article 20 of the Covenant was triggered, this generally indicated a failure of the State to fulfil other obligations, in particular the right to non-discrimination. Regarding the application of hate speech laws, the seminar also identified some objective criteria to avoid arbitrary application of these laws. Some of these criteria include: (a) the public intent of inciting discrimination, hostility or violence must be present for hate speech to be penalized; (b) any limitations on

freedom of expression should be clearly and narrowly defined and provided by law, and they must be necessary and proportionate to the objective they propound to achieve; (c) the least intrusive means insofar as freedom of expression is concerned should be used in order to prevent a chilling effect; and (d) the adjudication of such limitations must be made by an independent judiciary.

31. While arguing that hate speech laws are necessary and legitimate according to international standards, the Special Rapporteur cautioned against their subjective and overly broad application. More generally, he also insisted on the obligation of States to actively fight racism and discrimination. Fighting hate speech was, however, only one of several obligations States had to fight discrimination. Other obligations were contained in article 26 of the Covenant which stated that "the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any ground", including race, colour or national origin. Article 2 of the International Convention on the Elimination of All Forms of Discrimination provides an even higher standard of non-discrimination, including the need to adopt special measures.

32. In his statement, the Special Rapporteur recalled that the full implementation of the relevant international human rights standards was the most important defence to fight all manifestations of racism, including hate speech. He argued that hate speech was but a symptom of a more profound disease, which was racism and intolerance. There was therefore the need to attack these root causes, not only their external manifestation.

33. At the twelfth session of the Human Rights Council, the Special Rapporteur submitted, pursuant to Council resolution 10/22, a report on "the manifestations of defamation of religions, and in particular on the serious implications of Islamophobia, on the enjoyment of all rights by their followers" (A/HRC/12/38).

34. In view of the important developments that took place during the reporting period, the report takes stock of the ongoing conceptual debate on the issue of "defamation of religions" and incitement to religious hatred. In this regard, the Special Rapporteur refers to the above-mentioned report of the former mandate holder, the expert seminar organized by OHCHR on the links between articles 19 and 20 of the International Covenant on Civil and Political Rights, as well as to the agreement reached in the outcome document of the Durban Review Conference.

35. In the report, a brief overview is offered of the information sent to the Special Rapporteur by the Organization of the Islamic Conference on "Islamophobic incidents" and by the European Union Agency for Fundamental Rights on the discrimination and racially motivated crimes experienced by Muslims in the European Union. In this regard, the Special Rapporteur distinguishes between intolerant mentalities, incitement to religious hatred, religious discrimination and violence perpetrated against members of religious or belief communities. In the same chapter, he emphasizes that, when discussing incitement to racial or religious hatred, the interrelatedness of international human rights standards should be taken into account. In particular, he refers to the interdependence and interrelatedness of articles 18, 19 and 20 of the International Covenant on Civil and Political Rights, as well as article 4 of the International Convention on the Elimination of All Forms of Discrimination. In this context, he extensively refers to a joint statement on "freedom of expression and incitement to racial or religious hatred" presented with the Special Rapporteur on the protection and promotion of the right to freedom of

opinion and expression and the Special Rapporteur on freedom of religion or belief at a side event during the Durban Review Conference.[2]

36. In the last chapter of his report, the Special Rapporteur makes a number of conclusions and recommendations, proposing a way forward in international efforts to combat incitement to racial or religious hatred. In this regard, he reiterates the recommendation of his predecessor to encourage a shift away from the sociological concept of the defamation of religions towards the legal norm of non-incitement to national, racial or religious hatred. He also welcomes the consensus reached at the Durban Review Conference and recommends policymakers to rely on the robust and adequate language of the outcome document and to implement it domestically. Finally, he recommends that strong emphasis be put on the implementation of the core obligations of States relating to the protection of individuals and groups of individuals against violations of their rights incurred by hate speech and stresses the need to protect members of religious or belief communities from violation of their right to freedom of religion or belief.

2. Racism and poverty

37. The issue of racism and poverty has been addressed by the Special Rapporteur in his first annual report submitted at the eleventh session of the Human Rights Council (A/HRC/11/36), as well as in the framework of a side event on "Discrimination and poverty: exclusion and solutions in the new millennium" organized on 21 April 2008 by OHCHR during the Durban Review Conference.

38. In the Special Rapporteur's view, a central dimension of the fight against racism lies around the overlap between two key social indicators: class and race or ethnicity. While the links between race and poverty have yet to be further elucidated, national data, when available, unambiguously show that racial or ethnic minorities are disproportionately affected by poverty. Poverty puts members of minorities in a vicious circle. The lack of education, adequate housing and health care transmits poverty from generation to generation and perpetuates racial prejudices and stereotypes in their regard. Based on the body of empirical work and country visits carried out by the mandate, as well as on academic and policy-oriented research on this topic, the Special Rapporteur notes that the socio-economic vulnerability of racial or ethnic minorities is generally the result of historical legacies. Indeed, slavery, segregation or apartheid served not only to dehumanize people, but also created structural imbalances that remain to this day. Moreover, these unjust imbalances are also a result of the inaction of Governments.

39. In order to address the disproportionate levels of poverty experienced by the members of racial or ethnic minorities, the Special Rapporteur emphasizes three overarching priorities: (a) the collection of ethnically disaggregated data; (b) the central obligation to non-discrimination; and (c) the need for the enactment of special measures towards groups that suffered from decades or centuries of discrimination.

40. While the Special Rapporteur is conscious of the arguments against the collection of ethnically disaggregated data, he is of the view that the lack of such data has most often prevented policymakers from devising specific and appropriate

[2] The full text of the joint statement of the three Special Rapporteurs is available online at www2.ohchr.org/english/issues/racism/rapporteur/docs/Joint_Statement_SRs.pdf.

public policies aiming at redressing racial or ethnic imbalances. For that reason, he encourages a shift away from the debate on whether or not to collect ethnically disaggregated data, to a discussion on how to best collect these data. In this respect, the Special Rapporteur proposes some key principles for the collection of ethnically disaggregated data that can help to overcome the concerns of many States: the right to privacy; the principle of self-identification; and the involvement of minority communities at every stage of the exercise.

41. The Special Rapporteur would like to recall that the central obligation of States not to discriminate is unambiguously contained in international human rights law. Such obligation is particularly important with regard to the full enjoyment of economic, social and cultural rights, which have a profound impact on the socio-economic situation of minority communities.

42. Whereas non-discrimination is essential to create a level playing field for different communities, the Special Rapporteur believes that non-discrimination on its own does not provide for the correction of imbalances which are the result of historical legacies, such as slavery and segregation. In this regard, there continues to be a need for the enactment of special measures, as provided for in article 1.4 of the International Convention on the Elimination of All Forms of Racial Discrimination, towards groups that suffered from decades or centuries of discrimination, thus helping to transform the goal of integration and equal opportunities into a concrete reality for all.

43. In relation to the impact of the economic situation on racism, the Special Rapporteur also briefly addressed the possible negative consequences of the financial crisis on efforts to fight racism and xenophobia during the Wilton Park Conference on "Contemporary and future human rights challenges", held from 22 to 24 January 2009 in West Sussex, United Kingdom.

44. On that occasion, the Special Rapporteur warned that the economic slowdown forecast for the next years could contribute to the emergence of ethnic and racial tensions in areas where migrants live. He stated that such tensions often arose when there were problems in the economy as a whole, and in particular in the labour and housing markets. With soaring unemployment and decreasing salaries, some groups might try to manipulate public opinion to generate strong anti-immigration backlashes and to blame migrants for current economic problems. These xenophobic expressions were at times intertwined with racial prejudices and stereotypes, as migrants could often be differentiated based on their race or ethnicity.

45. The Special Rapporteur recalled that a set of measures was required to prevent the rise of such xenophobic feelings and their translation into policy. States had to be vigilant regarding their human rights obligations, in particular vis-à-vis migrants. In that regard, appropriate institutions and legislation were required to punish those who discriminated, incited or perpetrated acts of violence against foreigners or members of minorities. More broadly, political leaders had to be sensitive to the impact of racism, racial discrimination, xenophobia and related intolerance, reaching out to minorities and demonstrating constant vigilance regarding their human rights situation.

3. Genocide

46. On 21 January 2009, the Special Rapporteur participated in a seminar on the prevention of genocide organized by the Office of the United Nations High Commissioner for Human Rights. On that occasion, he recalled that genocide, ethnic cleansing and other war crimes were traditionally linked to the emergence of exclusionary ideologies based on race or ethnicity and that extreme forms of racism, often hidden under the guise of radical nationalism, could lead to unspeakable catastrophes. However, while it was clear that genocide was frequently accompanied by extreme forms of racism, the Special Rapporteur cautioned against sweeping causal statements. He highlighted that racism was a widespread and pervasive phenomenon, affecting countries in all regions of the globe, whereas genocide, on the other hand, had been confined to a limited number of cases which had taken place under specific circumstances.

47. Reflecting on the need to better understand the conditions under which racism leads to genocidal violence, the Special Rapporteur referred to the helpful efforts undertaken by the Committee on the Elimination of Racial Discrimination. The substantive work carried out by the Committee allowed for the identification of long-term and short-term factors leading to genocide. On the long term, the importance of addressing systematic discrimination against particular distinct groups was emphasized and early-warning signs helping to detect such systematic discrimination were identified by the Committee. Short-term factors were also indicated as being essential to explain how long-term causes were triggered into mass violence at particular times. Although a system of early warning was never fail proof, the Special Rapporteur stressed its absolute necessity against the crime of genocide. Such a system allowed identifying situations that should be placed on a "watch list" of countries at risk and also offered a sense of the long- and short- term measures required to overcome the problem.

48. While political solutions lay at the centre of these efforts, the Special Rapporteur underlined the set of human rights concerns which should also guide such political decisions, as they allowed for action on issues at the root causes of the conflict. Dealing with these root causes of ethnic conflict was considered by the Special Rapporteur as a fundamental strategy to prevent genocide. Indeed, the international community had often tried to remedy situations of conflict, while disregarding the real sources of the problem. As a consequence, racial or ethnic tensions remained long after a peace agreement was signed, only to lead to conflict recurring years later. An anti-racism and anti-discrimination approach was thus essential in post-conflict situations, particularly in post-genocide contexts, in order to ensure that such tragedies would not recur in the future. In particular, the Special Rapporteur stated that racial or ethnic fractures that opened during conflict needed to be addressed with broad programmes of national reconciliation that fostered inter-ethnic cooperation.

49. While national reconciliation must be a priority in a post-conflict situation, the Special Rapporteur also recalled that combating impunity was to remain on the top of the agenda. The investigation, prosecution and punishment of those responsible were an absolute necessity leading to a comprehensive and lasting reconciliation process. The culture of anti-impunity was at the core of the mandates of several international tribunals, which should be globally supported. Nonetheless, the Special Rapporteur considered that these international mechanisms were the last resort

option and that the domestic judiciary systems should bear the primary responsibility to prosecute and punish people who had incited to or participated in genocide. In conclusion, the Special Rapporteur strongly reiterated that the promotion and protection of human rights, democracy and rule of law at all times were the best defence against conflict, and also against genocide.

50. In addition to his above-mentioned individual statement, the Special Rapporteur contributed with seven other special procedures mandate holders to a joint statement,[3] which was delivered during the same seminar on the prevention of genocide.

51. Reflecting on effective strategies to prevent genocide and other mass atrocities, the eight special procedures mandate holders reaffirmed that owing to their independence, field activities and access to Governments and civil society, they constituted a useful instrument to collate and analyse in-depth information on serious, massive and systematic violations of human rights. They could also provide recommendations to the concerned Governments and the international community on the steps to be taken to defuse tensions at an early stage. Through their reporting to the General Assembly and the Human Rights Council, the special procedures endeavoured to contribute to a better understanding of and early warning on complex situations.

52. The eight special procedures mandate holders stressed the necessity for early warnings signals to reach the political and conflict-prevention bodies of the United Nations, in order to allow decision makers at the highest levels to take action with full knowledge of the facts on the ground. In that regard, it was underlined that one of the communication channels that special procedures could rely on more systemically was the Office of the Special Adviser on the Prevention of Genocide.

53. In conclusion, the eight special procedures mandate holders emphasized that prevention of genocide was an obligation of the international community and therefore constant vigilance by the United Nations was mandatory. At the same time, they also recalled that Member States had the primary responsibility to implement their international obligations. Ultimately, the best prevention against genocide or massive violence was to ensure respect for human rights, democracy and the rule of law, with particular attention to the principle of non-discrimination.

4. Discrimination based on descent

54. During the Durban Review Conference, the Special Rapporteur participated in a side event on "Communities empowered to resist discrimination and exclusion", organized by the International Movement against All Forms of Discrimination and Racism and Lutheran World Federation, on 22 April 2009.

55. Recalling that the issue of discrimination based on descent was addressed by special procedures mandate holders in their joint contribution to the preparatory process of the Durban Review Conference (A/CONF.211/PC/WG.1/5), the Special Rapporteur highlighted that the mandate holders had already expressed their serious concern about this form of discrimination.

[3] The joint statement by eight special procedures mandate holders is available online from www2.ohchr.org/english/events/RuleofLaw/docs/SProceduresJointStatement.pdf; see also A/HRC/10/25, paras. 44-50.

56. The Special Rapporteur referred to the estimated 250 million people around the world being at risk of violations of civil, political, social, economic and cultural rights, including violence, marginalization and discrimination, on the grounds of systems based on inherited status. Human rights violations could occur in a wide array of areas, including prohibition or limitations on the ability to alter inherited status, socially enforced restrictions on marriage outside the community, public and private segregation, including in housing and education, and access to public spaces and places of worship and public sources of food and water, limitation of freedom to renounce inherited or degrading occupations or hazardous work, as well as subjection to debt and bondage.

57. The Special Rapporteur recalled that since the 2001 World Conference against Racism, held in Durban, the issue of discrimination based on descent had been on the international agenda. Despite the objection of some States, the main human rights bodies working in the area of racism and discrimination had clearly stated that prohibition of this type of discrimination fell within the scope of existing instruments, in particular the International Convention on the Elimination of All Forms of Racial Discrimination. In that regard, the Special Rapporteur specifically referred to the Committee on the Elimination of Racial Discrimination, which concluded at its forty-ninth session, that "the situation of the scheduled castes and scheduled tribes falls within the scope of the Convention". In addition, the Committee also stated that discrimination on the grounds of caste constituted a form of racial discrimination and that "the term 'descent' had its own meaning and was not to be confused with race or ethnic or national origin". More broadly, in its general recommendation No. 29 (2002) concerning discrimination on the grounds of descent, the Committee further clarified its position by "strongly reaffirming that discrimination based on 'descent' includes discrimination against members of communities based on forms of social stratification such as caste and analogous systems of inherited status which nullify or impair their equal enjoyment of human rights".

58. As such, the Special Rapporteur reaffirmed that the legal framework on discrimination based on descent is unambiguous. Yet, it remains to be implemented properly. Robust action was required from Governments in order to advance in the fight against discrimination based on descent. The vital first step in addressing this issue was for States to recognize that discrimination on the grounds of descent constituted a form of racial discrimination prohibited by the International Convention on the Elimination of All Forms of Discrimination. In the absence of such recognition it would not be possible to effectively address the serious human rights violations and discrimination suffered by individuals and groups on grounds of caste and other systems of inherited status.

IV. Conclusions and recommendations

59. **In relation to the Durban Review Conference held from 20 to 24 April 2009, the Special Rapporteur hopes that the momentum gained during the review process will maintain its strength and that all pledges and commitments made in the outcome document of the Review Conference will be effectively implemented by States, which bear the primary responsibility in this respect. The Special Rapporteur recommends that concrete measures be identified at the domestic level and that a road map with realistic benchmarks be**

established by States in cooperation with their civil society for the implementation of the outcome document of the Conference.

60. Although some States chose not to participate in the Durban Review Conference, the Special Rapporteur calls on those States to nonetheless publicly express their support for the outcome document of the Review Conference and to commit to its implementation in order to fight racism, racial discrimination, xenophobia and related intolerance.

61. While measures need to be taken by States to fight incitement to racial or religious hatred, the Special Rapporteur would like to recommend that States refrain from adopting vague or overly broad restrictions on freedom of expression which have often led to abuse by the authorities and to the silencing of dissenting voices, particularly those of individuals and groups in vulnerable situations, such as minorities. Freedom of expression makes an essential contribution to the fight against racism and to the right to equality. It empowers individuals and groups in vulnerable situations to fight for their rights and allows them to provide a rational response to hate speech often targeting them.

62. The Special Rapporteur would like to recall that a global agenda at the national level against racism is the best way to effectively prevent hate speech. Although legislative measures are necessary, States should also resort to non-legislative measures, such as education and intercultural dialogue, in order to fight racism. In this regard, States should closely cooperate with their civil society in order to design, implement and evaluate the most appropriate and effective measures against racism.

63. In order to further clarify the existing links between race and poverty, the Special Rapporteur is of the view that it is necessary to collect ethnically disaggregated data. While he is fully aware of the arguments against the collection of such data, the Special Rapporteur recommends to shift from the debate on the need or not to collect ethnically disaggregated data to a thorough discussion on how to best collect them in order to comply with international standards and to avoid the misuse or manipulation of these data.

64. Owing to the potential adverse effects of the current financial and economic crisis on the efforts to fight racism and xenophobia, the Special Rapporteur recommends that States take appropriate and effective measures to prevent an eventual rise of xenophobic feelings, in particular vis-à-vis migrants who are in vulnerable situations. Special vigilance is indeed required in these times of economic turmoil and States should ensure that all necessary legislative and institutional safeguards are put in place in order to prevent a significant rise of xenophobia in their domestic society.

65. The Special Rapporteur believes that the most effective way to prevent genocide or massive violence perpetrated against a specific group of individuals is to ensure, at the national level, respect for human rights, democracy and the rule of law, with particular attention to the principle of non-discrimination. The same holds true in post-genocide or post-conflict situations. In this respect, the Special Rapporteur recommends that Governments take concrete measures aiming at fostering inter-ethnic cooperation so as to avoid the recurrence of ethnic conflicts.

66. **The establishment of an effective system of early warning is absolutely essential against the crime of genocide. It allows for the identification of situations which might become genocidal and provides a sense of the measures needed to counter the problems. In this regard, the Special Rapporteur would like to reaffirm its willingness to collaborate with the Office of the Special Adviser on the Prevention of Genocide.**

67. **In order to provide effective protection to individuals around the world being at risk of violations of civil, political, social, economic and cultural rights on the grounds of systems based on inherited status, the Special Rapporteur would like to encourage an international recognition that discrimination on the grounds of descent constitutes a form of racial discrimination prohibited by the International Convention on the Elimination of All Forms of Racial Discrimination.**

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Item 71 (b) of the provisional agenda*
Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Note by the Secretary General

The Secretary-General has the honour to transmit to the members of the General Assembly the report submitted by Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, in accordance with Human Rights Council resolution 6/29.

* A/64/150.

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Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health

Summary

Guaranteeing informed consent is fundamental to achieving the enjoyment of the right to health through practices, policies and research that are respectful of autonomy, self-determination and human dignity. An enabling environment that prioritizes informed consent links counselling, testing and treatment, creating an effective voluntary health-care continuum. Safeguarding informed consent along the health-care continuum is an obligation placed on States and third parties engaged in respecting, promoting and fulfilling the right to health. This requires States to ensure that information is fully available, acceptable, accessible and of good quality, and imparted and comprehended by means of supportive and protective measures such as counselling and involvement of community networks.

In the present report the Special Rapporteur considers the evolution of informed consent and discusses its main components in section II. In section III he discusses both the role of informed consent in realizing the right to health and the particular issues, duties and obligations required of States and health-care providers in guaranteeing informed consent in clinical practice, public health and medical research. Section IV outlines the need for law, policy and practice to take into account the vulnerability of certain individuals whose rights are compromised owing to deep-rooted power imbalances and structural inequalities, presenting particular responsibilities to States, health-care providers and third parties involved in ensuring non-discrimination in achieving the right to health. The Special Rapporteur emphasizes in the conclusion of this report the importance of prioritizing informed consent as a critical element of a voluntary counselling, testing and treatment continuum in the development of guidance for clinical practice, public health evidence, and medical research protocols, with special attention to the needs of vulnerable groups.

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I. Introduction

1. In its resolution 6/29 of 14 December 2007, the Human Rights Council extended the mandate of the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health (the right to health) for an additional three years. At its seventh session, held in June 2008, the Council nominated Anand Grover as the Special Rapporteur. He assumed his duties on 1 August 2008, succeeding Paul Hunt.

2. In accordance with his mandate, the Special Rapporteur will continue to further develop cooperation with relevant national and international actors, such as Governments, national human rights institutions, United Nations treaty bodies, international institutions, agencies, programmes, and independent experts, as well as with health professionals, academics, civil society organizations, community-based organizations of affected peoples and other stakeholders. The Special Rapporteur hopes to develop close cooperation with relevant government bodies to help them identify policies and programmes promoting the right to health.

3. Since March 2009, the Special Rapporteur has had fruitful discussions with numerous State representatives, the Joint United Nations Programme on HIV/AIDS (UNAIDS), the Global Fund to Fight AIDS, tuberculosis and Malaria, civil society organizations and other Special Procedures mandate holders.

4. The Special Rapporteur has participated in numerous consultations and conferences on the right to health, including interventions at: the Erasmus Observatory on Health Law in Rotterdam, the Netherlands; the National Law School of India University in Bangalore, India; meetings on maternal mortality in Geneva and New Delhi; the Asian and the Pacific Regional Consultation on Maternal Health in Bali; the International Congress on AIDS in Asia and the Pacific in Bali; the Global Mental Health Summit in Athens; and the Global Conference on Meeting Nutritional Challenges in New Delhi. The Special Rapporteur also organized a consultation in Kathmandu, on the right to health involving civil society organizations in the countries of the South Asian Association for Regional Cooperation.

5. In the present report, the Special Rapporteur examines the fundamental role that informed consent plays in respecting, protecting and fulfilling the right to health, discussing specifically the areas of clinical practice, public health and medical research.

6. This report discusses the need for laws and international instruments to take into account the vulnerability of certain individuals whose rights are compromised owing to deeply rooted power imbalances and structural inequalities, presenting particular responsibilities to States and health-care providers to protect the human dignity and autonomy of all persons.

7. In the recommendations, the Special Rapporteur urges: (a) States to meet their obligations to safeguard informed consent through legislative, political and administrative mechanisms; (b) health-care providers to be cognizant that, according to their duty to act in the best interests of the patient, they are key players in protecting informed consent; (c) national and international bodies to emphasize the importance of informed consent as a fundamental aspect of the right to health in relevant policy and practice.

II. Background

8. The concept of consent has evolved for centuries to arrive at its current meaning. In the aftermath of the Nuremberg Trials, increased international recognition of patients' rights developed in the twentieth century,[1] defining the responsibility of health-care providers and States responsibilities to the patient.[2] In 1947, the Nuremberg Code asserted that the voluntary consent of the human subject to medical research is necessary under all circumstances. The Declaration of Helsinki (1964) further developed the Code principles and tied them to the ethical duties of physicians, as outlined in the Declaration of Geneva (1948). In 1994, the World Health Organization Amsterdam Declaration on Patients' Rights required informed consent as a prerequisite for any medical intervention, guaranteeing also the right to refuse or halt medical interventions.[3]

9. Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.[4] Important components of informed consent are discussed below.

A. Respect for legal capacity

10. Competency to consent is a status known as legal capacity generally determined by the ability to comprehend, retain, believe and weigh information provided in arriving at a decision.[5] Legal capacity is presumed in adult persons and renders them the right to consent to, refuse or choose an alternative medical intervention. A patient's actual decision — however contrary to professional advice — has no bearing on legal capacity.

11. Children's legal capacity is approached differently throughout the world, such as by use of a competency test to establish the sufficient maturity to provide consent or requirements for parental consent.

12. Supportive measures (such as alternative and augmentative communication) may be required to assist the exercise of legal capacity and respect the wishes of persons who, temporarily (owing to transitory states such as loss of consciousness, panic, fear or confusion) or permanently, are not able to exercise legal capacity. Only in a life-threatening emergency in which there is no disagreement regarding absence of legal capacity[6] may a health-care provider proceed without informed consent to perform a life-saving procedure.

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[1] See, e.g., *Schloendorff v. Society of New York Hospital*, 211 NY 125 (1914) (USA).
[2] See article 7, International Covenant on Civil and Political Rights.
[3] See article 3, Amsterdam Declaration on patients' rights, ICP/HLE 121 (1994).
[4] See J. W. Berg et al., *Informed consent: legal theory and clinical practice* (2001).
[5] See, e.g., *Re C* [1994] 1 All ER 819 (UK). Also applied in *Re C* [1997] 2 FLR 180 (UK).
[6] See, e.g., *Re T* [1992] 4 All ER 649 (UK).

B. Respect for personal autonomy

13. Informed consent is valid only when documented prior to a medical procedure and provided voluntarily, meaning without coercion, undue influence or misrepresentation. While consent for simple procedures may sometimes be implied by a patient, more complex, invasive treatments require explicit consent.

14. Coercion includes conditions of duress such as fatigue or stress.[7] Undue influences include situations in which the patient perceives there may be an unpleasant consequence associated with refusal of consent.[8]

C. Completeness of information

15. Informed consent requires disclosure of the associated benefits, risks and alternatives to a medical procedure. Just as a patient has the right to receive information in giving consent, a patient has the right to refuse such information in giving consent, providing disclosure of such information has been appropriately offered.

16. The concept of the "prudent patient" finds its legal origins in the Canterbury doctrine developed in the United States which requires disclosure of all aforementioned information to the patient prior to obtaining consent. Modified objective consent, developed in Canada,[9] additionally accounts for the patient's subjective perspective in ensuring that information is accessible and acceptable to the patient's specific circumstances and is most conducive to respecting the rights of the patient.

17. The power imbalance created by reposing trust and unequal levels of knowledge and experience inherent in the doctor-patient relationship — owing especially to the complexities of modern medicine — makes effective communication especially challenging. This is exacerbated by the power imbalances resulting from class, gender, ethnicity and other socio-economic factors.

III. Right to health and informed consent

18. Guaranteeing informed consent is a fundamental feature of respecting an individual's autonomy, self-determination and human dignity in an appropriate continuum of voluntary health-care services. Informed consent in health, including (but not limited to) clinical practice, public health and medical research, is an integral part of respecting, protecting and fulfilling the enjoyment of the right to health as elaborated in article 12 of the International Covenant on Economic, Social and Cultural Rights and enshrined in numerous international and regional human rights treaties and national constitutions.[10]

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[7] See *Beausoleil v. The Sisters of Charity* (1964), 53 DLR 65 (Canada).

[8] See K. Forrester and D. Griffiths, *Essentials of Law for Health Professionals* (2005).

[9] See *Reibl v. Hughes* (1980) 2 S.C.R. 880 (Canada).

[10] See article 25, Universal Declaration of Human Rights; article 12, International Covenant on Economic, Social and Cultural Rights; Convention on the Elimination of All Forms of Discrimination against Women; Convention on the Rights of the Child and Convention on the Rights of Persons with Disabilities.

19. Informed consent invokes several elements of human rights that are indivisible, interdependent and interrelated. In addition to the right to health, these include the right to self-determination, freedom from discrimination, freedom from non-consensual experimentation, security and dignity of the human person, recognition before the law, freedom of thought and expression and reproductive self-determination.[11] All States parties to the International Covenant on Economic, Social and Cultural Rights have a legal obligation not to interfere with the rights conferred under the Covenant, including the right to health.[12] Safeguarding an individual's ability to exercise informed consent in health, and protecting individuals against abuses (including those associated with traditional practices) is fundamental to protecting these rights.

20. Several regional instruments protect the right to informed consent. These include: the Council of Europe's Convention on Human Rights and Biomedicine (Oviedo Convention) adopted in 1997, and its Additional Protocol concerning Biomedical Research (European Treaty Series (ETS) 195); the Charter of Fundamental Rights of the European Union;[13] and the European Council's and Parliament's Clinical Trials Directive.[14]

21. The Committee on Economic, Social and Cultural Rights, the World Health Organization (WHO), the first Special Rapporteur, and many others have developed an analysis of the right to health to make it easier to understand and apply.[15] Committee on Economic, Social and Cultural Rights general comment No. 14 elucidates the requirements of respecting, protecting and fulfilling the right to health, encompassing both freedoms and entitlements. The entitlements include services that are available, accessible, acceptable and of good quality. The freedoms include the right to control one's health and body, and freedom from non-consensual interference.[16]

22. Key elements of the analytical framework relevant to this report include the propositions that: (a) all health services, including information, should be available, acceptable, accessible, and of good quality. States must ensure a culturally and ethically acceptable health-care continuum; (b) participation in all health-related decision-making is critical at the community, national and international levels; States are obligated to support individuals and community networks in ensuring that health services are provided on the basis of informed consent; (c) States have a duty to respect, protect and fulfil the enjoyment of the right to health of all persons. The duty to protect is greater when persons are vulnerable due to health, social, economic and political status.[17]

23. Crucially, a rights-based approach in the context of informed consent addresses structural inequalities, which can significantly impact mental or physical

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[11] See articles 2, 3, 5, 6 and 16, Universal Declaration of Human Rights; articles 1, 2, 3, 7, 9, 10, 16, 18, 19, 24, 25, 26 and 27, International Covenant on Civil and Political Rights.

[12] See article 30, Universal Declaration of Human Rights; article 5, International Covenant on Economic, Social and Cultural Rights.

[13] See article 3, European Union Charter of Fundamental Rights (2000).

[14] See directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001.

[15] See E/CN.4/2003/58, A/58/427; WHO, *Human Rights, Health and Poverty Reduction Strategies* (2005); Physicians for Human Rights, *Deadly Delays: Maternal Mortality in Peru* (2007).

[16] See Committee on Economic, Social and Cultural Rights, general comment No. 14, para. 8.

[17] See Committee on Economic, Social and Cultural Rights, general comment No. 14, paras. 12 and 17.

conditions or the relationship with the health-care provider. Barriers in the communication of information demand counselling services and community involvement supporting adequate comprehension and decision-making. Health information needs to be of the highest quality, freely available on a non-discriminatory basis, accessible to the individual's particular communication needs (including special physical or cultural circumstances), and presented in a manner culturally and otherwise acceptable to the person consenting. Communication should be cognizant of varying levels of comprehension and not be too technical, complex, hasty, or in a language, manner or context that the patient does not understand.

A. Clinical practice

24. A rights-based approach in the clinical setting means that counselling, testing and treatment must be treated as a voluntary health-care continuum. The process of achieving informed consent links available, acceptable, accessible and quality information to similar services in a voluntary testing and treatment continuum facilitated by appropriate counselling. Prioritizing the importance of patient autonomy and dignity in achieving informed consent through proper counselling is the first step in linking to, for example, HIV-testing to the delivery of services on a voluntary, non-discriminatory basis. This is imperative in yielding the greatest individual and public health benefits owing to the direct correlation between patient trust and cooperation and medical efficacy.

25. The role of the health-care provider in providing information, as well as being cognizant of and minimizing threats to voluntary decision-making, is critical in achieving the right to health.[18] However, this role in promoting a health-care continuum on the basis of informed consent is often compromised in settings where staff and resources are inadequate.

26. Importantly, a rights-based approach addresses structural barriers to achieving informed consent within the appropriate health-care continuum. Such an approach is especially cognizant of the power imbalances resulting from inequalities in knowledge, experience and trust between the health-care provider and the individual, particularly those from vulnerable groups. Importantly, stigma and discrimination serve as disincentives for such patients to seek out services and providers to treat patients equally.

27. Compulsory, and, at times, routine testing is disempowering and frequently compromises human rights. Such testing is coercive and generally results in inadequate provision of information and counselling, compromising informed consent and deterring individuals from accessing test results and appropriate services. A community-mobilizing environment that links testing to treatment and care services, conversely, encourages voluntary testing while decreasing stigma and discrimination.[19]

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[18] See Physicians for Human Rights, General Guideline 13, *Dual Loyalty and Human Rights in Health Professional Practice: Proposed Guidelines and Institutional Mechanisms* (2003).

[19] See UNAIDS, *HIV voluntary counselling and testing: gateway to prevention and care* (2002).

28. The right to consent to treatment also includes the right to refuse treatment,[20] regardless of a procedure's advisability.[21] However, health-care providers should discourage patients from refusing life-saving procedures by emphatically highlighting the medical consequences.

29. A patient, or a patient's permanent legal representative, may authorize a health-care proxy to provide consent when the patient is unable to do so. In the absence of a proxy, if a person is authoritatively judged not to have legal capacity due to a transitory physical or mental state such as unconsciousness, a health-care provider may resort only to a life-saving emergency procedure,[22] and only in the absence of a clear prior or immediate indication of refusal.[23] Unless previously authorized as a proxy, the next-of-kin cannot consent on behalf of the patient but ought to be consulted for relevant, albeit non-binding, information that may illuminate the preferences of the patient.[24] Safeguards against abuse, such as requirements for a third party medical opinion, should be in place.

B. Public health

30. Public health measures should always strive for voluntary participation to be fully effective and minimize compromising the rights to privacy and self-determination of the person. According to the 1985 Siracusa Principles, any restriction from the International Covenant on Civil and Political Rights must be non-discriminatory; in accordance with the law, legitimate and necessary; and the least restrictive reasonably available alternative.[25] Importantly, restrictions must be fully respectful of dignity, human rights and fundamental freedoms.[26] Interference with freedom of movement should be used only as a last resort,[27] when voluntary measures cannot reasonably be expected to succeed.[28] The recent severe acute respiratory syndrome (SARS) and influenza A(H1N1) pandemics have raised concerns about the extent to which individual rights have been compromised by quarantine measures.[29]

31. A rights-based approach to public health requires that any restrictions give the utmost attention to a continuous process of counselling, testing and treatment within an optimally healthful environment. Any limitations of informed consent must be

[20] See, e.g., *Malette v. Shulman et al.*, (1990) 67 D.L.R. (4th) 321 (Canada).

[21] See CEDAW/C/36/D/4/2004.

[22] See *Moore v. Webb*, 345 S.W.2d 239 (Mo.App. 1961) (US).

[23] See *Public Health Trust of Dade County v. Wons*, 541So. 2d 96 (Fla. 1989) (US); *Re T* [1992] 4 All ER 649 (UK).

[24] See *Re T* [1992] 4 All ER 649 (UK).

[25] See E/CN.4/1984/4.

[26] See article 3, WHO International Health Regulations (2005).

[27] See WHO, *WHO Guidance on human rights and involuntary detention for xdr-th control* (2007).

[28] See WHO, *Ethical considerations in developing a public health response to pandemic influenza. Ethics, equity, trade and human rights* (2007).

[29] See G. L. Burci and R. Koskenmaki, "Human Rights Implications of Governance Responses to Public Health Emergencies: The Case of Major Infectious Disease Outbreaks", *Realizing the Right to Health* (2009), pp. 346-358.

substantiated by scientific evidence and implemented with participation, transparency and accountability on the principles of gradualism and proportionality.[30]

32. Any protocols for routine testing should require informed consent and be accompanied by anti-stigma sensitization to avoid exacerbating conditions of marginalization. Compulsory testing, unless justified by public health requirements, must never be used as a means of policing private behaviour. Criminalizing behaviour that is harmful to one's health is counter-productive to achieving a voluntary counselling, testing and treatment continuum.

33. Successful HIV/AIDS testing is underpinned by conditions of counselling, informed consent and confidentiality.[31] International guidelines recommend that public health legislation demand that HIV/AIDS testing be performed only on the basis of individual informed consent[32] and grounded in an approach protecting human rights.[33] However, current guidelines for provider-initiated testing and counselling, which do not make testing conditional on the availability of treatment, undermine the testing-treatment continuum and long-term prevention. The "simplified pre-test information" prescribed by provider-initiated testing and counselling revokes one of the most important HIV/AIDS-related interventions — comprehensive, individualized pre-test counselling and information — thereby forgoing an important opportunity for prevention information and services for those who test negative. In addition, the routine offer of provider-initiated HIV testing and counselling on an "opt-out" basis — inferring consent in the absence of explicit refusal (rather than seeking voluntarily initiated consent) — has been recommended for settings with generalized HIV/AIDS epidemics.[34] However, those tested under provider-initiated testing and counselling, particularly when from marginalized groups,[35] often feel compelled to accept.[36] The scale-up of testing services without pre-test counselling has the potential to further marginalize these groups and thwart long-term prevention measures and need re-examination.

34. Just as linking appropriate counselling and treatment to voluntary testing serves as an enabling incentive for testing, compulsory treatment measures are a disincentive. Policies of compulsory confinement are therefore often medically unsound, failing to acknowledge that ventilated confinement is conducive to transmission of airborne illness; consensual, community-based care models lead to

[30] See L. O. Gostin, "Public Health Strategies for Pandemic Influenza: Ethics and the Law", *JAMA*, vol. 295, issue 14 (2006), pp. 1700-1704; S. Gruskin and B. Loff, "Do Human Rights have a Role in Public Health Work?" *The Lancet*, vol. 360 (2002), p. 1880.

[31] See UNAIDS/WHO, "UNAIDS/WHO Policy Statement on HIV Testing" (2004).

[32] See OHCHR and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006).

[33] See UNFPA and WHO, *Sexual and Reproductive Health of Women Living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children in resource-constrained settings* (2006), para. 9.

[34] See WHO/UNAIDS, *WHO/UNAIDS Guidance on provider-initiated HIV testing and counselling in health facilities* (2007).

[35] See S. Weiser et al., "Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns", *PLoS Medicine*, vol. 3, issue 7 (2006), p. 395.

[36] A report from Botswana found that two thirds of women felt they could not decline. Physicians for Human Rights, *Epidemic of Inequality: Women's Rights and HIV/AIDS in Botswana and Swaziland* (2007). See also S. Weiser et al. (2006), "Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns", *PLoS Medicine*, vol. 3, issue 7 (2006); A. Welbourn, "Into the Firing Line: Placing young women and girls at greater risk", *AIDS Legal Network* (2008).

better treatment outcomes.[37] Nevertheless, non-infectious tuberculosis-positive individuals have been forcibly detained, sometimes even in prisons.[38] In accordance with the principles of proportionality and gradualism, any confinement measure should be as least restrictive as possible, favouring, for instance, home — over hospital — confinement.[39] Informed consent should be applied to treatment administered in any isolation and quarantine approaches, supporting and encouraging the completion of therapy on a voluntary basis.[40]

C. Medical research

35. Informed consent of participants is imperative for conducting medical research, and is thus mandated by international standards.[41] Each potential subject must be adequately informed of the aims, methods, anticipated benefits and potential risks of the research. Consent may be withdrawn at any time, so the informed consent process must be continuous, inclusive of new adverse developments.[42] Concerns that results will be consequently undermined cannot justify withholding of information, and researchers must be cognizant of the "therapeutic misconception" leading the patient to expect medical benefit despite the possibility of placebo.[43]

36. A rights-based approach to medical research means that special protections must be in place to ensure that the autonomy of potential participants, particularly those from vulnerable groups, is not compromised as a result of power imbalances inherent in the researcher-subject relationships. Research conducted in low-literacy populations requires additional efforts to facilitate comprehension of technical concepts. Research involving individuals from vulnerable groups should seek the participation of a representative organization that may be able to assist participants throughout the process. Special considerations must also be made regarding undue incentives, clinical vulnerability, language and cultural barriers, double standards, unnecessary risk, and collection of tissue samples.

37. Incentives offered for participation in research must be limited to adequate compensation for time, effort and adverse consequences of participation. In limited-resource settings, access to financial or medical resources often becomes an undue incentive to consent or disincentive to withdraw consent.[44] Researchers and review boards should be particularly cognizant of such circumstances.

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[37] See Rio Communities' Declaration at the 3rd Stop TB Partners Forum, March 2009.

[38] See R. Coker, "Detention and mandatory treatment for tuberculosis patients in Russia", *The Lancet*, vol. 358, issue 9279 (2001), pp. 349-350.

[39] See A. Boggio et al., "Limitations on human rights: Are they justifiable to reduce the burden of TB in the era of MDR- and XDR-TB?" *Health and Human Rights*, vol. 10, issue 2 (2008), pp. 121-126.

[40] See WHO, *Good Practice in Legislation and Regulations for TB Control: An Indicator of Political Will* (2001).

[41] See article 7, International Covenant on Civil and Political Rights.

[42] See article 24, European Treaty Series 195.

[43] See P. S. Appelbaum et al., "The therapeutic misconception: informed consent in psychiatric research", *International Journal of Law and Psychiatry*, vol. 5 (1982), pp. 319-329.

[44] See F. van Loggerenberg et al., "Ethical challenges in undertaking HIV/AIDS research in resource constrained settings: Experiences with sex workers at truck stops in South Africa", *International Conference on AIDS* (2002), p. 14.

medicines against scientifically unjustifiable data exclusivity, which results in known information regarding potential risks and benefits being withheld from patients, obviating informed consent.

42. Researchers seeking permission for future use of identifiable DNA tissue samples must inform individuals of all possible uses.[54] Guidelines for approval of modified informed consent requirements for any testing of anonymous tissue samples should make allowances based only on clear scientific evidence regarding public health benefits.[55]

IV. Vulnerable groups and informed consent

43. Informed consent, as an integral part of the right to health, must be guaranteed with every protection against stigmatization or discrimination on any grounds, as provided by article 2 of the Universal Declaration of Human Rights and article 2, paragraph 2, of the International Covenant on Economic, Social and Cultural Rights, and reinforced by article 11 of the United Nations Educational, Scientific and Cultural Organization Universal Declaration on Bioethics and Human Rights (2005).

44. The Committee on Economic, Social and Cultural Rights has recently reiterated the imperative of non-discrimination in its general comment No. 20,[56] articulating especially the importance of taking a flexible approach in addressing discrimination based on "other status" reflecting the experience of marginalized social groups. It emphasizes further the important role of supportive, and permanent, when necessary, measures to ensure non-discrimination.

45. In addition to the imbalance of power, experience and trust inherently present in the doctor-patient relationship, structural inequalities can result in the voluntary or informed nature of consent being significantly compromised. Appropriate support mechanisms to help overcome subsequent challenges to achieving informed consent, including community involvement and comprehensive counselling along the health-care continuum, are critical in protecting the rights of vulnerable groups.

46. Certain groups deserve special consideration regarding the protection of informed consent as a result of vulnerabilities stemming from economic, social and cultural circumstances. Principles 17 and 18 of the Yogyakarta Principles, for instance, highlight the importance of safeguarding informed consent of sexual minorities. Health-care providers must be cognizant of and adapt to the specific needs of lesbian, gay, bisexual, transgender and intersex persons. Such elements of vulnerability significantly overlap and exacerbate inequalities; however, certain groups are addressed separately below for the purposes of this report.

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[54] See P. A. Marshall, *Ethical challenges in study design and informed consent for health research in resource-poor settings*, WHO (2007).

[55] See, e.g., L. M. Kopelman, "Informed consent and anonymous tissue samples: The case of HIV seroprevalence studies", *Journal of Medicine and Philosophy*, vol. 19, issue 6 (1994), pp. 525-552.

[56] See E/C.12/GC/20.

A. Children

47. The Convention on the Rights of the Child demands respect for the child's evolving capacities and due weight to be given to the child's views according to age and maturity.[57] Risks and benefits of medical interventions must be adequately conveyed to the child, and, given sufficient maturity, the child's informed consent should be sought.[58] The recently adopted general comment on article 12 of the Convention on the Rights of the Child, stipulates that "States Parties need to introduce legislation or regulations to ensure that children have access to confidential medical counselling and advice without parental consent, irrespective of the child's age, where this is needed for the child's safety or well-being.... The right to counselling and advice is distinct from the right to give medical consent and should not be subject to any age limit."[59]

48. As "minors" before the law, children often have their rights relegated to a legal guardian, compromising their exercise of autonomy; varying maturity levels makes appropriately assessing legal capacity very difficult. Children from marginalized communities and those in institutional care are particularly vulnerable to being subjected to non-consensual medical interventions.[60] Social preconceptions among adults can present barriers to children's right to sexual and reproductive health services and information, and while some countries protect it,[61] in many countries, parental consent requirements impede access.[62] States must ensure that adolescents have access to appropriate health information and services regardless of parental consent,[63] particularly those concerning sexual and reproductive health.[64] Given sufficient maturity, adolescents may request confidential health services[65] and information.[66]

49. Health-care providers should strive to postpone non-emergency invasive and irreversible interventions until the child is sufficiently mature to provide informed

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[57] See articles 5 and 12(1), Convention on the Rights of the Child.

[58] See articles 3, 13 and 17, Convention on the Rights of the Child; Convention on the Rights of the Child general comments No. 3, para. 20.

[59] See Convention on the Rights of the Child, general comment No. 12, para. 101.

[60] See A/61/299; WHO/SEARO, "Synthesizing experiences from countries in the region: Similarities, differences, lessons learnt", *Increasing adolescents' access to health services for HIV and Adolescent Sexual and Reproductive Health* (2006).

[61] In the United States, the Public Health Service Act (Title 42 of the United States Code (1946)) requires that federally funded family planning clinics provide confidential services without parental consent to all minors. However, some state level laws continue to limit access; T. J. Valvano, "Legal Issues in sexual and reproductive health care for adolescents", *Clinical Pediatric Emergency Medicine*, vol. 10 (2009), pp. 60-65.

[62] See UNFPA et al., "Report Card, HIV Prevention for Girls and Young Women: India (2007), Kenya (2008), Swaziland (2007), Thailand (2006), and Peru (2006)"; K. L. Dehne and G. Riedner, *Sexually transmitted infections among young people. The need for adequate health services*, WHO CAH (2005); P. Mahery, "Consent laws influencing children's access to health care services", *South African Health Review* (2006), pp. 167-180; American Psychological Association, *Parental Consent and Adolescent Reproductive Health* (2000).

[63] See Convention on the Rights of the Child, general comment No. 4; A/CONF.171/13, para. 7.

[64] See CRC/C/KEN/CO/2, para. 49.

[65] See Convention on the Rights of the Child, general comment No. 4.

[66] See article 16, Convention on the Rights of the Child.

consent.[67] Safeguards should be in place to protect children from parents withholding consent for a necessary emergency procedure.

50. Even where laws are supportive, appropriate training of health workers is necessary to avoid continued denial of services to adolescents without parental consent.[68] Additional efforts must be made to ensure that information and services are child-friendly and age-accessible through appropriate opening hours, staff training and sensitization, and special considerations for information sources and presentation, such as peer health approaches.[69]

B. Elderly persons

51. Although the ageing population continues to grow worldwide, policies and support structures protecting the rights of elderly persons are grossly inadequate.[70] Elderly persons are taken advantage of due to perceived ignorance and helplessness, as well as actual physical or mental frailty such as that caused by degenerative disease resulting in decreased ability to provide informed consent. Elderly persons in hospice care are especially vulnerable to denial of autonomy and dignity[71] due to the absence of appropriate oversight, particularly in cases of non-consensual drug therapy.[72]

52. States must ensure that elderly persons enjoy the right to health, including informed consent, at the same level as any other person.[73] As guaranteed by article 12 of the Convention on the Rights of Persons with Disabilities, disability, including age-related, cannot itself justify limitation of legal capacity. Research conducted on persons suffering from degenerative disease must be in accordance with the requirements of the Declaration of Helsinki for such research.[74]

53. Supportive measures, such as public initiatives to improve elderly persons' access to relevant information in easy-to-understand formats and through established channels of communication such as social security networks, should be implemented. International guidelines and national systems should be developed to regulate and monitor hospice care practices to ensure that the elderly are supported in making informed health-care decisions, and that their human dignity and autonomy are not neglected due to their vulnerability.

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[67] This is particularly problematic in the case of intersex genital surgery, which is a painful and high-risk procedure with no proven medical benefits; see, e.g., Colombian Constitutional Court, Sentencia SU-337/99 and Sentencia T-551/99.

[68] WHO/SEARO, "Synthesizing experiences from countries in the region: Similarities, differences, lessons learnt", *Increasing adolescents' access to health services for HIV and Adolescent Sexual and Reproductive Health* (2006).

[69] Family Health International, "Making reproductive health services youth-friendly" (1999).

[70] See WHO and the International Network for the Prevention of Elderly Abuse, *Missing Voices: Views of older persons on elder abuse* (2002).

[71] See WHO, "Abuse of the elderly", *World Report on Violence and Health* (2002).

[72] See United Kingdom House of Commons Health Committee, *Elder Abuse* (2004).

[73] See Convention on Economic, Social and Cultural Rights, general comment No. 6, paras. 34 and 35; Convention on Economic, Social and Cultural Rights, general comment No. 20, para. 29.

[74] See Declaration of Helsinki, paras. 27 and 28.

C. Women

54. Gender inequalities reinforced by political, economic and social structures result in women being routinely coerced and denied information and autonomy in the health-care setting. Women's sexual and reproductive health rights demand special considerations; pregnant women are at times denied consent along an appropriate health-care continuum justified by the best interests of the unborn child.

55. Social and legal norms limit women's independent access to sexual and reproductive health services.[75] Evidence[76] reveals that women are often entirely excluded from decision-making in health care. Women are often coerced into "routine" HIV/AIDS testing in ante-natal care settings without links to counselling and treatment.[77] Forced sterilization or contraception continues to affect women,[78] injuring their physical and mental health and violating their right to reproductive self-determination,[79] physical integrity and security.[80] Women are often provided inadequate time[81] and information[82] to consent to sterilization procedures, or are never told or discover later that they have been sterilized. Numerous countries have taken inadequate action against individuals who perform non-consensual sterilizations, and some have even sanctioned such procedures in national "family planning" initiatives with anti-natalist undertones based on racial or ethnic discrimination. Stigma and discrimination against women from marginalized communities, including indigenous women, women with disabilities and women living with HIV/AIDS, have made women from these communities particularly vulnerable to such abuses.[83]

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[75] See Rajalakshmi, "Reducing reproductive rights: spousal consent for abortion and sterilization", *Indian Journal of Medical Ethics*, vol. 3 (2007); Family Health International, "Reproductive health providers routinely face ethical issues, including those with conflicting principles", *Network*, vol. 21, issue 2 (2002); WHO Regional Office for the Eastern Mediterranean, *Cross-cutting gender issues in women's health in the Eastern Mediterranean region* (2007).

[76] See U. Senarath, "Women's autonomy in decision-making for health care in South Asia", *Asia Pacific Journal of Public Health*, vol. 21, issue 2 (2009), pp. 137-143; N. Qureshi and B. T. Shaikh, "Women's empowerment and health: the role of institutions of power in Pakistan", *Eastern Mediterranean Health Journal*, vol. 13, issue 6 (2007).

[77] See C. Eyakuze et al., "From PMTCT to a more comprehensive AIDS response for women: a much-needed shift", *Developing World Bioethics*, vol. 8, issue 1 (2008), pp. 33-42.

[78] See E/CN.4/1999/68/Add.4.

[79] See Convention on the Elimination of All Forms of Discrimination against Women, general recommendation 19.

[80] See IRIN, Office for the Coordination of Humanitarian Affairs, *Africa: When Culture Harms The Girls — The Globalization of Female Genital Mutilation* (2005).

[81] See Inter-American Commission on Human Rights, *Maria Mamerita Mestanza Chávez v. Peru*, Case 12.191, 2000.

[82] See CEDAW/C/36/D/4/2004; Center for Reproductive Rights, *Body and Soul: Forced Sterilization and Other Assaults on Roma Reproductive Freedom* (2003).

[83] See, e.g., K. H. and *Others v. Slovakia*, Appl. No. 32881/04, European Court of Human Rights, 2009; International Community of Women Living with HIV/AIDS, "The forced and coerced sterilization of HIV positive women in Namibia" (2009); L. Dowse, "Moving Forward or Losing Ground? The Sterilization of Women and Girls with Disabilities in Australia", paper presented to Disabled Peoples' International World Summit, Winnipeg, 8-10 September 2004.

56. Regrettably, female genital mutilation continues to be performed throughout the world, even on two-year-old girls.[84] It is physically and mentally injurious,[85] has no health benefits, and is a violation of bodily integrity and personal autonomy of the girl/woman. Female genital mutilation is virtually never a woman's independent decision, owing to its strong cultural significance concerning virginity, marriage eligibility and social status.[86]

57. The need for special protections guaranteeing a woman's right to informed consent is reinforced by the Beijing Declaration.[87] Women have the right to freely consent to or refuse services (including sterilization services) that are non-coercive and respectful of autonomy, privacy and confidentiality;[88] and information provided by properly trained personnel.[89] Any requirement for preliminary authorization by a third party is a violation of a woman's autonomy.[90] Sexual and reproductive health services must be free from coercion, discrimination or lack of information.[91] States must ensure absence of any form of coercion in reproductive health services, including testing procedures for sexually transmitted infections or pregnancy as a pre-condition of employment.[92] The Beijing Platform highlights the right of a woman to make reproductive decisions free of discrimination, coercion and violence; and the International Conference on Population and Development (ICPD) Programme of Action protects the right to decide freely and responsibly the number and spacing of one's children.[93] Forced sterilization, when committed as part of a widespread or systematic attack, is a crime against humanity.[94]

58. Reproductive freedom should never be limited by individuals or States as a family planning method, HIV/AIDS prevention, or any other public health agenda. States should ensure that laws respect the woman's right to autonomy and decision-making and do not support substituted consent by spouses and that harmful traditional practices like female genital mutilation are eliminated as a matter of urgency.[95]

59. Health-care providers are critical actors in ensuring that women are provided adequate information, especially information regarding reversible family planning

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[84] Estimates suggest that 3 million girls in sub-Saharan Africa, Egypt, and the Sudan are subjected to female genital mutilation each year. UNICEF, "Changing a Harmful Social Convention: Female Genital Mutilation/Cutting", *Innocenti Digest*, vol. 12 (2005).

[85] See WHO, "Female genital mutilation and other harmful practices", Factsheet No. 241 (2008).

[86] Noteworthy is the case of a Kenyan MP whose political opponents opposed her running for office during the 2002 elections on the grounds that she had not been circumcised. IRIN (2005), Office for the Coordination of Humanitarian Affairs, *Africa: When Culture Harms The Girls — The Globalization of Female Genital Mutilation* (2005).

[87] See A/CONF.177/20, para. 89.

[88] See views of the Committee on the Elimination of Discrimination against Women, CEDAW/C/36/D/4/2004; *K. H. and Others v. Slovakia*, Appl. No. 32881/04, European Court of Human Rights, 2009.

[89] See A/54/38, paras. 20 and 31.

[90] See A/54/38, para. 21.

[91] See A/CONF.171/13.

[92] See A/54/38, para. 22.

[93] See A/CONF.171/13.

[94] See article 7(1)(6), A/CONF.183/9 Rome Statute of the ICC.

[95] See article 5, Convention on the Elimination of All Forms of Discrimination against Women; Convention on the Elimination of All Forms of Discrimination against Women, general recommendation 14.

options,[96] and personnel must be adequately trained and sensitized in this respect. Health-care providers should strive to collaborate with women's groups that provide support at the community level in the provision of information, counselling, empowerment and social sensitization to gender equality.

60. Guidance concerning situations of maternal-foetal conflict should capitalize on the potential of proper counselling and comprehensive support services through women's networks to mitigate restrictions of autonomous decision-making of the woman and any potentially harmful effects to the child.[97]

D. Ethnic minorities

61. Ethnic minorities, as well as migrants, can be at particular risk of having their exercise of autonomy compromised owing to language and cultural barriers. Having lost the protection of their State of origin, refugees and asylum-seekers are especially vulnerable.

62. Compulsory, or routine, HIV/AIDS testing of asylum-seekers, refugees, IDPs and other persons of concern is a violation of human rights and unjustifiable through public health standards.[98] Any such testing discourages immigrants from seeking timely and appropriate health care owing to fears of deportation and discrimination. Mandatory human papillomavirus (HPV) vaccination of immigrant women[99] similarly constitutes a discriminatory practice. Any such procedures may only be applied to migrants according to standards applied to naturalized citizens in a non-discriminatory manner.

63. All minorities, including refugees and migrant workers, are protected against discrimination in health care.[100]

64. States should take steps to make health-care information and services specifically accessible, acceptable and available to all minorities through translation services, culturally friendly services and anti-discrimination sensitization.[101]

E. Indigenous peoples

65. Traditional norms concerning collective autonomy, as well as the language and cultural barriers addressed above, necessitate additional considerations regarding the informed consent of indigenous peoples. Indigenous peoples are especially vulnerable

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[96] See FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, "Ethical considerations in sterilization", *Recommendations on Ethical Issues in Obstetrics and Gynaecology* (2006), p. 74.

[97] See e.g. Open Society Institute, *Women, Harm Reduction and HIV* (2007).

[98] See UNHCR, "10 Key Points on HIV/AIDS and the Protection of Refugees, IDPs, and Other Persons of Concern".

[99] See United States Citizenship and Immigration Services, I-693, Report of Medical Examination and Vaccination Record.

[100] See 1951 Convention Relating to the Status of Refugees and its 1967 Protocol; 1990 International Convention on the Protection of the Rights of All Migrant Workers and their Families; Convention on Economic, Social and Cultural Rights, general comment 20, para. 15.

[101] See, e.g., European Centre for Social Welfare Policy and Research, *Access to health care for migrants, ethnic minorities, and asylum seekers in Europe* (2009).

in medical research involving their communities owing to undue incentives and significant power imbalances.

66. The informed consent of indigenous peoples is protected by their equal right to health enshrined in all relevant human rights treaties and explicitly also in article 24, paragraph 2 of the United Nations Declaration on the Rights of Indigenous Peoples.

67. In communities where promoting individual consent over traditional collective consent would be detrimental to the provision of health-care services, considerations must be made to respect traditional practice, provided individual consent to any such practice is explicitly taken. In communities where the positioning of trust to a single health-care provider is highly valued, minimizing the turnover of health-care providers should become a priority.

68. For medical research, WHO principles require that the consent of recognized representatives of the community be sought — and periodically reaffirmed — according to the community's leadership protocols.[102] However, this is distinctive and secondary to individual consent.[103] Any problems that arise must be addressed at both levels.[104] Assistance from an umbrella organization to which the community freely belongs — if available and without conflict of interest — should be sought.

F. Persons with disabilities

69. Persons with disabilities often suffer from unjustified perception of being incompetent or dangerous to themselves or others. Such prejudices, coupled with existing laws and practices limiting legal capacity, often compromise their informed consent.[105]

70. Many States, with or without a legal basis, continue to allow for the prolonged detention of persons with mental disabilities in institutions without their free and informed consent.[106]

71. Forced sterilization of girls[107] and women[108] with disabilities has been documented internationally and is even being currently proposed in Rwanda.[109] Persons with disabilities, including children, continue to be exposed to non-consensual medical experimentation.[110]

72. The Convention on the Rights of Persons with Disabilities reaffirms that the existence of a disability is not a lawful justification for any deprivation of liberty, including denial of informed consent.[111] States must provide persons with

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[102] See WHO, *Indigenous peoples and participatory health research* (2009).

[103] See Canadian Institutes for Health Research, *CIHR Guidelines for Health Research Involving Aboriginal People* (2007).

[104] See WHO, *Indigenous peoples and participatory health research* (2009).

[105] See A/58/181.

[106] See A/63/175.

[107] See Independent Expert for the Secretary-General's Study on Violence against Children, *World Report on Violence against Children* (2009).

[108] See United Nations Enable, "Factsheet on Persons with Disabilities" (2009).

[109] See Human Rights Watch, "Compulsory HIV testing, sterilization of disabled violate rights", Human Rights Watch Press Release (2009).

[110] See A/63/175, para. 40.

[111] See articles 14 and 25, Convention on the Rights of Persons with Disabilities.

disabilities equal recognition of legal capacity, care on the basis of informed consent, and protection against non-consensual experimentation; as well as prohibit exploitation and respect physical and mental integrity.[112] States have the obligation to provide (on a permanent basis if necessary) any appropriate supports, including total support, for persons with disabilities to exercise their legal capacity to the greatest possible extent.[113] This is particularly relevant in the provision and comprehension of information, as underlined by Convention on Economic, Social and Cultural Rights general comment No. 20, which emphasizes the importance of implementing supportive measures for persons with sensory impairments.[114]

73. Policies and legislation sanctioning non-consensual treatments lacking therapeutic purpose or aimed at correcting or alleviating a disability, including sterilizations, abortions, electro-convulsive therapy and unnecessarily invasive psychotropic therapy, violate the right to physical and mental integrity and may constitute torture and ill-treatment.[115]

74. Persons with disabilities who are not able to exercise their legal capacity must be treated according to the standards acceptable for those with disabilities in equal circumstances. Mechanisms for total support for decision-making and consent (as in all other cases) should come into effect only when a person is authoritatively determined to require it in order to exercise legal capacity.

G. Persons living with HIV/AIDS

75. As discussed in section III, people living with HIV/AIDS often discover their status as the result of involuntary testing procedures. They subsequently face stigma and can be deterred from accessing appropriate services, undermining long-term prevention and treatment efforts.[116] Lack of information and the relative powerlessness of communities involved in HIV/AIDS clinical trials (especially when vulnerable groups are targeted) further compromise informed consent.

76. Examples of violations include non-consensual testing, sterilizations and abortions, and compromised confidentiality of women living with HIV/AIDS,[117] HIV/AIDS-related clinical trials conducted among pregnant women, sex workers and people who use drugs have raised a number of ethical concerns[118] relating to, among other things, the inadequate provision of information.

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[112] See articles 12, 15, 16, 17 and 25, Convention on the Rights of Persons with Disabilities.

[113] See A/HRC/10/48, para. 43.

[114] See E/C.12/GC/20.

[115] See A/63/175, paras. 40 and 48.

[116] See, e.g., P. Nieburg et al., *Expanded HIV Testing*, Center for Strategic and International Studies (2005); A. Welbourn, "Into the Firing Line: Placing young women and girls at greater risk", AIDS Legal Network (2008); S. Maman et al., "High rates and positive outcomes of HIV-serostatus disclosure to sexual partners … in Dar es Salaam, Tanzania", *AIDS and Behavior*, vol. 7, issue 4 (2003), pp. 373-382.

[117] See International Community of Women living with HIV/AIDS, *The forced and coerced sterilization of HIV positive woman in Namibia* (2009); Centre for Reproductive Rights, *Forcibly sterilized woman files international case against Chile* (2009).

[118] See UNAIDS, "Meeting ethical concerns over HIV trials", (2007); E. J. Mills et al., "Designing research in vulnerable populations: lessons from HIV prevention trials stopped early", *BMJ*, vol. 33 (2005), pp. 1403-1406.

77. The International Guidelines on HIV/AIDS and Human Rights emphasize the need to protect the informed consent of persons living with HIV/AIDS, especially with regards to sexual and reproductive health.[119] Guidelines for HIV-related research clearly require proper informed consent, including any testing involved.[120]

78. Appropriate provision of information in obtaining consent for voluntary HIV/AIDS treatment extends to supportive counselling to facilitate understanding the importance of adherence to long-term treatment. Networks of people living with HIV/AIDS should be meaningfully involved in the planning and delivery of services and in facilitating achievement of informed consent.

H. Persons deprived of liberty

79. Persons deprived of liberty are often subjected to violations of rights that go beyond the scope necessary for the purposes of confinement; such risks are exacerbated by high incidence of mental illness and drug dependence. Conditions of deprivation and the inherent imbalance of power between prison staff and prisoner can contribute to undue influences in decision-making. The permissibility of medical experimentation on prisoners has been an issue of serious concern since the Nuremberg Trials, particularly concerning offers of amnesty as incentive. Prisoners of conscience require additional protections, as they may wish to surrender their rights as a legitimate form of protest.

80. Prisoners' rights may not be limited beyond what is necessitated by the condition of incarceration, including the right to health enjoyed by free persons, and freedom from medically harmful research.[121] Prisoners of war are likewise afforded "every guarantee of hygiene and healthfulness" extending to informed consent.[122] Medically unjustified experimentation is never allowed on prisoners of war.[123]

81. Despite legislative compliance, most countries continue to allow compulsory testing in practice, such as drug testing through the Prisons Act in the United Kingdom.[124] Such testing is usually not linked to treatment, and States must reverse such measures and ensure adherence to legislation protecting prisoners' rights.

82. Prisoners participating in HIV/AIDS research trials face the threat of stigma and discrimination owing to a lack of confidentiality in the prison setting.[125] Guidelines for the ethical review of research in prisons should be cognizant of coercive realities in the prison setting.

83. Hunger strikers are often subjected to force-feeding and restraint.[126] The World Medical Association Declaration of Tokyo (1975) and Declaration of Malta

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[119] See OHCHR and UNAIDS, *International Guidelines on HIV/AIDS and Human Rights* (2006).

[120] See UNAIDS/WHO, *Ethical considerations in HIV prevention trials* (2007).

[121] See principles 5 and 9, "Basic Principles for the Treatment of Prisoners" (General Assembly resolution 45/111); General Assembly resolution 43/173.

[122] See article 22, Third Geneva Convention (1949).

[123] See Article 130, Third Geneva Convention (1949); General Assembly resolution 61/30.

[124] See UK Prisons Act (1994).

[125] See N. N. Dubler and V. W. Sidel, "On research on HIV infection and AIDS in correctional institutions", *The Milbank Quarterly*, vol. 67, issue 2 (1989), pp. 171-207.

[126] See D. J. Nicholl et al., "Forcefeeding and restraint of Guantanamo Bay hunger strikers", *The Lancet*, vol. 367 (2006), p. 811.

(1991) prohibit the use of non-consensual force-feeding of hunger strikers, including prisoners.

84. The organs of executed prisoners are sometimes removed without prior consent, particularly where consent for organ donation is presumed if the body is not collected by the family.[127] The World Medical Association has condemned this practice,[128] and States should take immediate action to end it.

I. Sex workers

85. Sex workers and their families are often denied basic civil rights and subjected to forced testing and treatment often as a consequence of stigma, discrimination and stereotypes that label them as vectors of disease. Mandatory, compulsory and, in some circumstances, routine testing and treatment approaches fail to address the effects of stigma, discrimination, violence and power imbalances on a sex worker's ability to negotiate protection during sex or seek health services. Rather than changing or even challenging the subordinate position of sex workers, mandatory testing and treatment can reinforce their stigmatization.

86. Public health rationales have in some instances led to mandatory sexually transmitted infection and HIV/AIDS testing and treatment, accompanied by punitive measures in the case of a positive result.[129] Sex workers from some countries report refusal of health services without mandatory HIV/AIDS testing.[130] Such circumstances can often serve as disincentives for use of testing and health services as an entry point to treatment and care.[131]

87. Relevant protocols and practices should be reviewed to ensure that health information and services are available to sex workers through support and peer networks that can ensure confidentiality and informed consent, as well as strengthen sex workers community networks in protecting the enjoyment of the right to health.[132]

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[127] See Human Rights Watch-Asia, "Transplant organs removed without executed prisoners' consent", 20 April 2006; T. Diflo, "Use of organs from executed prisoners", *The Lancet*, vol. 364 (2004), pp. 30-31.

[128] See World Medical Association Resolution on Physicians' Conduct Concerning Human Organ Transplantation, adopted by the forty-sixth World Medical Association General Assembly (1994).

[129] See International Gay and Lesbian Human Rights Commission, *Transvestite Sex Workers suffer Arbitrary Arrest, Forced HIV testing and other Indignities* (2000); Center for Advocacy on Stigma and Marginalization, *Rights-based sex worker empowerment guidelines? An Alternative HIV/AIDS Intervention Approach to the 100% Condom Use Programme* (2008).

[130] See WHO and the Global Coalition on Women and AIDS, *Violence against sex workers and HIV prevention* (2005).

[131] See Center for Advocacy on Stigma and Marginalization (2008), *Rights-based sex worker empowerment guidelines? An Alternative HIV/AIDS Intervention Approach to the 100% Condom Use Programme* (2008).

[132] See WHO and the Global Coalition on Women and AIDS (2005), *Violence against sex workers and HIV prevention* (2005).

J. Persons who use drugs

88. Persons who use drugs are often perceived as being dangerous to themselves and unable to make the "right" decision. Prohibitions against their behaviour threaten their ability to refuse testing and treatment. Informed consent is obviated by compulsory drug and alcohol testing when such testing is linked to non-consensual treatment consequences.

89. In addition to being generally ineffective,[133] largely conducive to relapse[134] and demotivating,[135] compulsory drug dependence treatment is often associated with prolonged isolation,[136] detention without judicial oversight and government registrations constituting violations of the right to privacy.[137] In some countries, persons who use drugs are subjected to compulsory treatment and HIV/AIDS testing,[138] and to "therapy" constituting cruel, inhuman or degrading treatment or punishment nationally endorsed by existing legal frameworks for drug control.[139] Persons undergoing drug dependence treatment are often unaware of its nature, duration or experimental status.[140] Conditions in compulsory treatment centres often present additional health risks owing to exposure to infectious diseases[141] and lack of qualified staff able to address emergencies or provide medically managed drug treatment.[142]

90. Treating persons who use drugs as criminals is counterproductive from a right to health perspective. States should change legislation that supports criminalization based on non-consensual testing. Any routine drug or alcohol testing should be consensual to encourage appropriate conditions of counselling and treatment, and implemented in a non-discriminatory, transparent and inclusive way. Testing and

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[133] See Health Services Assessment Collaboration, "The Effectiveness of Compulsory, Residential Treatment of Chronic Alcohol or Drug Addiction in Non-Offenders", *INAHTA Briefs*, issue 38 (2008).

[134] See M.-L. Brecht et al., "Coerced treatment for methamphetamine abuse: differential patient characteristics and outcomes", *The American Journal of Drug and Alcohol Abuse*, vol. 3 (2005), pp. 337-356.

[135] See, e.g., T. Wild et al., "Perceived coercion among clients entering substance abuse treatment: structural and psychological determinants", *Addictive Behaviours*, vol. 23, issue 1 (1998), pp. 81-95; J. Platt et al., "The prospects and limitations of compulsory treatment of drug addiction", *Journal of Drug Issues*, vol. 18, issue 4 (1988), pp. 505-525; A. Stevens et al., "Quasicompulsory treatment of drug dependent offenders: an international literature review", *Substance Use and Misuse*, vol. 40 (2005), pp. 269-283.

[136] See WHO Western Pacific Region, *Assessment of compulsory treatment of people who use drugs in Cambodia, China, Malaysia and Viet Nam: An application of selected human rights principles* (2009).

[137] See Open Society Institute, *Human rights abuses in the name of drug treatment: Reports from the field* (2009).

[138] See J. E. Cohen and J. J. Amon, "Health and Human Rights Concerns of Drug Users in Detention in Guangxi Province, China", *PLoS Med*, vol. 5, issue 12 (2008), p. 234.

[139] See R. Pearshouse, "Patients, not criminals? An assessment of Thailand's compulsory drug dependence treatment system", *HIV/AIDS Policy and Law Review*, vol. 14, issue 1 (2009).

[140] See Open Society Institute, *Human rights abuses in the name of drug treatment: Reports from the field* (2009).

[141] See R. Pearshouse, "Patients, not criminals? An assessment of Thailand's compulsory drug dependence treatment system", *HIV/AIDS Policy and Law Review*, vol. 14, issue 1 (2009).

[142] See WHO Western Pacific Region, *Assessment of compulsory treatment of people who use drugs in Cambodia, China, Malaysia and Viet Nam: An application of selected human rights principles* (2009).

treatment protocols should treat drug dependence like any other health-care condition.[143]

91. Guidelines for drug dependence treatment should endorse only voluntary evidence-based treatment (such as opioid substitution therapy) and provide for adequate training of staff. Treatment that is not evidence-based should never be used, and voluntary treatment services should be scaled up and accessible to marginalized groups.

V. Conclusions and recommendations

92. **While informed consent is commonly enshrined in the legal framework at the national level, it continues to be compromised in the health-care setting, and thus compromise the voluntary health-care continuum, as a result of the power imbalance created by reposing trust and unequal levels of knowledge and experience inherent in doctor-patient and researcher-subject relationships. Structural inequalities exacerbated by stigma and discrimination result in individuals from certain groups being disproportionately vulnerable to having informed consent compromised.**

93. **Guaranteeing informed consent is a fundamental dimension of the right to health and requires adopting policies, practice and protocols that are respectful of autonomy, self-determination and human dignity. An enabling environment that prioritizes informed consent links counselling, testing and treatment in an effective health-care continuum. Such continuum, in turn, is a primary feature of the rights-based approach to health. Consequently, safeguarding informed consent along the health-care continuum is an obligation placed on States and third parties engaged in respecting, promoting and fulfilling the right to health. This requires States to ensure that health information is: (a) fully available, acceptable, accessible, and of good quality; and (b) imparted and comprehended by means of supportive and protective measures such as counselling and involvement of community networks.**

94. **The Special Rapporteur therefore recommends that States consider whether they are meeting their obligations to safeguard informed consent as a critical element of the right to health through their legal framework and judicial and administrative mechanisms, including policies and practices to protect against abuses. Specifically, States should ensure the protection of vulnerable groups, required, inter alia, by the Geneva Conventions, the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women, and the Convention on the Rights of Persons with Disabilities. Particular attention should be given to the protection of the rights of persons with disabilities regarding recognition of legal capacity.**

95. **States should ensure the implementation and monitoring of legal and administrative frameworks, policies and practices and relevant capacity-building for health-care providers, research institutions and other stakeholders in this regard. This includes addressing implementation barriers at the community level and those entrenched in social and cultural norms and practices, especially gender inequalities.**

[143] See A/HRC/10/44.

96. Any limitations on informed consent and associated elements of the health-care continuum required for public health should be critically examined to ensure that they: (a) are fully respectful of individual rights and liberties; and (b) pay the utmost attention to supporting a continuous process of counselling, testing and treatment.

97. States should ensure that informed consent is given priority in medical research, with relevant protocols requiring mechanisms to support the continuous provision and comprehension of information, as well as withdrawal of consent. Ethics review boards must develop, as a matter of urgency, additional safeguards to prevent double standards that can compromise informed consent in developing countries.

98. The particular needs of vulnerable groups should be given special consideration and information and interventions adapted accordingly, through the meaningful participation of those concerned and their representative organizations in all processes. To ensure non-discrimination, States must: (a) actively identify and overcome structural sources of vulnerability and stigma and discrimination; and (b) subsequently develop and provide the tools and mechanisms necessary for the protection of vulnerable groups. The Special Rapporteur draws attention to the recommendations made throughout the report in this respect.

99. The protection of informed consent within the health-care continuum should be considered as an essential component in the evaluation of the evidence used to inform policy and practice in the delivery of health-care services and public health goals.

100. All policies guiding distribution of global health financing and technical assistance in the context of multi- and bilateral cooperation should emphasize the importance of, and require, informed consent within the health-care continuum and support the establishment of relevant mechanisms for its protection.

101. Monitoring mechanisms to identify situations compromising informed consent within the health-care continuum need to be established. Mechanisms for redress should be made available at the local, regional and international levels to ensure that those whose actions threaten human dignity and autonomy in the health-care setting are held accountable for their actions and further violations are prevented.

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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Report of the United Nations Special Rapporteur on the right to education

Note by the Secretary-General

The Secretary-General has the honour to transmit to the members of the General Assembly the interim report on the right to education submitted by Vernor Muñoz, Special Rapporteur on the right to education, in accordance with Human Rights Council resolution 8/4.

* A/64/150.

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Summary

The present report is submitted pursuant to Human Rights Council resolution 8/4, which renewed the mandate of the Special Rapporteur on the right to education and asked him to present a report to the General Assembly. The Special Rapporteur presents a summary of the activities he participated in and attended in the discharge of his mandate, covering the period since the finalization of the last report presented to the General Assembly (A/63/292).

The Special Rapporteur then raises the issue of lifelong learning and human rights. As learning must be seen as a lifelong experience, it remains an incomplete process. Thus lifelong learning encompasses formal, informal and non-formal education. Initiatives launched to promote lifelong learning on the national as well as international level, in both governmental and non-governmental sectors, are shown in the present report. The Special Rapporteur is of the opinion that lifelong learning needs to move closer to the context of human rights, as this is essential for progression to a society free from all forms of prejudice, exclusion and discrimination and the realization of a global human rights culture. The Special Rapporteur also presents the concept of human rights learning and shows its mutual interdependence with lifelong learning, and draws upon a number of concepts and initiatives concerning human rights learning that he has seen in practice.

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I. Introduction

1. The present report is submitted pursuant to Human Rights Council resolution 8/4, adopted on 18 June 2008, which requested the mandate to report also to the General Assembly.

2. In June 2009, the Special Rapporteur attended the eleventh session of the Human Rights Council and presented his annual thematic report, which focused on the right of persons in detention to education.[1] Persons in detention face endemic violations of their right to education. The report demonstrated a need to redouble efforts to respect, protect and fulfil that right. The report showed that prisoners faced significant and complex educational challenges, due to a range of environmental, social, organizational, and individual factors. The preparation of the report benefited greatly from the active and constructive engagement of many Governments, international organizations, academics, non-governmental organizations and prisoners. The Special Rapporteur sent a comprehensive questionnaire to all Member States and a number of intergovernmental and non-governmental organizations. The answers received offered a wealth of different perspectives on education in detention, which form the basis of a number of recommendations contained in the report.

3. The Special Rapporteur also presented, as addenda to that report, the summary of communications received and sent in relation to the discharge of his mandate,[2] as well as the report of his mission to Guatemala[3] (July 2008), and to Malaysia[4] (February 2007), which could not be presented at an earlier stage.

4. Since presenting his last report to the General Assembly, the Special Rapporteur has undertaken a mission to Paraguay (April 2009) and is to undertake a mission to Mongolia (October 2009), on which he will report to the Human Rights Council at the next cycle of presentation of reports.

II. Activities of the Special Rapporteur

5. The Special Rapporteur thought it important to present a summary of the activities he participated in and attended in the discharge of his mandate, since the finalization of the last report presented to the General Assembly.[5]

6. The Special Rapporteur gave a keynote speech at a workshop organized by the Colombian Coalition for the Right to Education (Campaña colombiana por el derecho a la educación) and the Latin American Campaign for the Right to Education (Campaña latinoamericana por el derecho a la educación, CLADE) on 11 and 12 August 2008, in Bogotá. The workshop presented the latest report of the Special Rapporteur on education in emergencies. It served to interchange and reinforce strategies for the right to education between CLADE and its Colombian counterpart and to organize a specific seminar free in Colombia with the participation of local organizations from civil society.

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[1] A/HRC/11/8.
[2] A/HRC/11/8/Add.1.
[3] A/HRC/11/8/Add.3.
[4] A/HRC/11/8/Add.2.
[5] A/63/292.

7. On 3 September 2008, the Special Rapporteur was invited as a lecturer to the symposium "All kids are VIPs — Integration through Education — Fairness for All" in Gütersloh, Germany, organized by the Bertelsmann Foundation, with representatives from business, politics, migrant organizations and academia. The symposium discussed strategies for promoting integration and harnessing the learning potential of students of immigrant origins in schools.

8. On 19 September 2008, the Special Rapporteur participated as the keynote speaker at the Day of General Discussion dedicated to "The right of the child to education in emergency situations" organized by the Committee on the Rights of the Child in Geneva. The purpose of the Day of General Discussion was to foster a deeper understanding of the contents and implications of the Convention on the Rights of the Child as they relate to articles 28 and 29. Representatives of Governments, United Nations human rights mechanisms, United Nations bodies and specialized agencies, as well as national human rights institutions, non-governmental organizations and individual experts were invited to take part. The discussion focused on issues which have proved most problematic for States Parties to address, and for which States were to benefit from the views and experiences of the wide range of partners the discussion day was able to bring together. The meeting was divided into two working groups: one focused on the implementation of article 28 of the Convention on the Rights of the Child, concerning access to education, in the context of emergencies, with a particular focus on education as a right and how this is fulfilled. This group discussed how to prioritize education as an emergency measure, as an essential protection tool and one which must be included in the humanitarian response from the very beginning of the emergency through to the development phase, allowing for the continuation of children's education and building their future capacities. The other group focused on the implementation of article 29 of the Convention on the Rights of the Child, concerning the content of education, considering the particular educational rights and needs of children in emergency situations, including the role of education as a life-saving measure. At the end of its 49th session, the Committee adopted a set of recommendations aimed at improving the implementation of the Convention.

9. On 15 October 2008, the Special Rapporteur was invited to participate in the International Conference on Education in Emergency Situations organized by Save the Children in Rome. At that conference, the results of a two-year research project conducted by that organization, together with partners, were presented and the campaign "Rewrite the Future" was updated with a new report from war-torn and post-conflict countries. The Special Rapporteur also had the opportunity to meet with the Inter-ministerial Committee on Human Rights of Italy during that visit.

10. From 25 to 28 November 2008, the International Conference on Education was held in Geneva. The Special Rapporteur was invited to the conference and moderated the workshop entitled "Inclusive Education: Public Policies" on 26 November 2008. The Conference was attended by Ministers of Education and delegations from 153 Member States, along with representatives of 20 intergovernmental organizations, 25 non-governmental organizations, foundations and other institutions of civil society, and focused on the theme "Inclusive education: the way of the future". The participants affirmed that inclusive quality education was fundamental to achieving human, social and economic development, agreed that Governments, as well as all other social actors, had an important role in providing a quality education for all and, in doing so, should

recognize the importance of a broadened concept of inclusive education that addressed the diverse needs of all learners and that was relevant, equitable and effective. The Conference concluded that, despite the current global financial crisis, funding for education should remain a priority and the crisis should not serve as a justification for a reduction in the allocation of resources to education at both the national and international levels.

11. On 15 and 16 December 2008, the Special Rapporteur, along with representatives of United Nations human rights treaty bodies, participated in the inaugural session of the Forum on Minority Issues held at Geneva. The Forum, organized under the guidance of the Independent Expert on minority issues, Gay McDougall, gathered participants from Member States, non-governmental organizations, and academic institutions from all over the world to discuss the issue of "Minorities and the Right to Education". A number of experts, most of them belonging to minority groups and representing all regions of the world, were invited to share their experiences regarding access to education for members of minority groups.

12. From 2 to 6 January 2009, the Special Rapporteur attended the international congress on "The Preventive System and Human Rights" promoted by the Youth Ministry Department of the Salesian Congregation in Rome, which focused on the importance of human rights education and education for human rights towards world citizenship. More than 300 participants, including many educators, from 130 countries took part in the World Congress, which aimed at networking and exchanging best practices and experiences of the Don Bosco Preventive System.

13. From 5 to 7 March 2009, the Special Rapporteur participated in the "International Seminar on gender violence and sexual and reproductive health" organized by Eurosocial (Regional Project for Social Cohesion in Health in Latin America) in San José, Costa Rica. The seminar gathered representatives from the health and education sectors, as well as human rights activists, physicians and academics from the entire Latin American region.

14. On 11 and 12 March 2009, the Special Rapporteur attended the international conference entitled "Where peace begins: the pivotal role of education for lasting peace", organized by Save the Children, the Norwegian Foreign Ministry and the Government of Bosnia and Herzegovina, which was in Sarajevo. Participants included mediators and peace practitioners, Government officials, Nobel Peace Prize laureates, education authorities and experts, United Nations and civil society representatives. The aim of the conference was to strengthen the coordination of, and commitment to, international efforts to integrate education in peacemaking processes, examine why education needs to be prioritized in peace processes, how quality education promotes peace, and the role of education in peace mediation. The conference was also an opportunity to contribute to the conclusions of the March 2009 United Nations General Assembly thematic debate on education in emergencies which followed shortly thereafter.

15. On 18 March 2009, the Special Rapporteur was invited to participate in an informal General Assembly thematic debate on education in emergencies, organized by the President of the General Assembly at United Nations Headquarters in New York. The debate was opened by the Secretary-General and the Special Envoy of the United Nations Educational, Scientific and Cultural Organization (UNESCO) on basic and higher education and three different panels were organized: Rights and

promises: education in emergencies: why we need to act now; Practicalities and possibilities: how to make it work; and Shared accountability: ways to move forward. The thematic debate was organized to highlight the critical importance of education in emergencies, to remind Member States of their commitments and obligations, and to provide clear guidance on the practicalities and possibilities of providing education in emergencies. States were also reminded of their obligation to provide children with quality education, and the international community was made aware that its experience and expertise could provide guidance on how this could and should be achieved.

16. On 28 and 29 May 2009, the Special Rapporteur was the keynote speaker at the Conference on the Institutionalization of Democracy and Human Rights in Education for the Southern African Development Community in Johannesburg, South Africa. The Conference, organized by the Open Society Institute of Southern Africa and partners, focused on the institutionalization of democracy and human rights in education, education in conflict and post-conflict situations and on the regional integration and dialogue on democracy and human rights in education. Participants included Government officials, academics and human rights activists from southern African countries.

17. On 7 June 2009, the Special Rapporteur attended a conference on inclusive education in Oldenburg, Germany, organized by the city of Oldenburg and various local civil society organizations, entitled "Education is a right, not a commodity". At that conference, the Special Rapporteur presented his activities and examples of various thematic and mission reports, and gave examples of inclusive education and the danger of the privatization of education. The situation of persons with disabilities, as well as persons from migrant backgrounds and their access to education, were also discussed.

18. From 24 to 26 July 2009, the Special Rapporteur held meetings with civil society organizations in Guatemala City and partners, and on 25 July, he attended a Forum organized by PRODESA, entitled "The situation of education of indigenous peoples" and a meeting on "Monitoring the recommendations of the Special Rapporteur on the right to education" in Sololá City.

19. From 4 to 8 August 2009, the Special Rapporteur was invited by the Latin American Campaign for the Right to Education (Campaña Latinoamericana por el Derecho a la Educación, CLADE) to participate in a meeting on the planning of strategies against discrimination in education, on the Campaign for the ratification of the Convention against Discrimination in Education (UNESCO, 1960) and on regional strategies before the Inter-American Commission on Human Rights. The meeting was followed by the second meeting of the Deliberative Council of the Regional Fund of the Civil Society for Education (Fondo Regional de la Sociedad Civil para la Educación — FRESCE), in São Paulo, Brazil.

III. Lifelong learning and human rights

A. Background

20. For the Special Rapporteur, the purpose of education is to construct useful knowledge that will enhance people's lives.[6] Learning is unavoidable, as action entails knowledge and, conversely, knowledge implies action.[7] Therefore, learning may be discussed as a human right in order to teach how to learn as one of the most important pedagogical objectives.[8]

21. To learn means to adapt to and collaborate with others, as well as to transform the environment. It is the process by means of which we communicate, propose ideas and carry them through; it becomes society's organizing principle. Learning is an essential element of life, a phenomenon that makes evolution possible.

22. The learning process impacts upon human beings by means of cognitive processes that are representative of culture and society. Although the learning process is inherent to humans, it can also be stimulated and developed through education. Human rights protect learning from an ethical and legal point of view. Accordingly, the Special Rapporteur has referred to the right to learn as a higher right, as it protects vital processes.[9] The right to learn should also be seen as a cognitive process because it involves reflexive and practical actions carried out during everyday tasks. This process also departs from the reality of a learning society and can also fully grow in a context that has been defined by Hugo Assmann as a "cognitive ecology"[10] and in which all human beings participate.

23. Education boosts the learning process and gives it a holistic meaning, therefore becoming a reference point and a stimulus to it.[11] Education also has a unique quality that enables it to be present already shortly after birth, and to play an important role throughout the lifespan of every individual.

24. Education therefore simultaneously encompasses our past and future; it is an aspect of life that comprehends everything that makes human development possible. It is thus an organizing principle of every society. However, it can also organize, entrench and strengthen prejudice, exclusion and discrimination. National educational systems should aim to prevent this from occurring.

25. The construction of national educational systems, beginning with the industrial revolution and the building of the modern nation state, has been based on macroeconomic considerations that have accentuated societal and patriarchal inequalities and asymmetries. This societal framework has given form to educational languages, concepts and models and has had a dramatic impact on the institution of learning by validating and reproducing stereotypes, prejudices and inequities.

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[6] See http://www2.ohchr.org/english/issues/education/rapporteur/index.htm.

[7] See Maturana, H. and Varela, F. G., *El arbol del conocimiento*, Editorial Universitaria, Santiago de Chile, 1998, p. 13.

[8] Muñoz V., "One word encompassing many worlds: notes on education for the XXIst century", http://www.volint.it/scuola/web_congress/documenti/munoz_4jan_en.pdf, p. 4.

[9] Ibid., note 7.

[10] Assmann, Hugo, "Placer y ternura en la educación, hacia una sociedad aprendiente"; Narcea, Madrid, 2002.

[11] Ibid., note 7.

26. The existence of such a structure that binds practically all social, political, economic and cultural relationships constitutes a formidable barrier to progress in the realization of human rights.[12] Poverty and limited access to education, health and other services already contribute to the denial of economic, social and cultural rights to historically discriminated groups. However, societal traditions multiply the obstacles that prevent discriminated groups from fully participating in decision-making processes.[13] This situation is also reflected in the framework of societal inequalities and asymmetries, which promote the myth of macroeconomic development being the main objective of education, which is usually considered merely an expense and a form of service subordinate to the interests of the economy and not a human right.

27. However, economic growth does not always lead to human development, nor does an adequate budget for education guarantee that resources will be invested to the benefit of those who need them the most. It is therefore improper to consider the fulfilment of the right to education as a determining factor of productive or commercial efficiency, especially since there is also no clear relationship between per capita income and social equity. Furthermore, this utilitarian perspective is detrimental to the dignity of traditionally discriminated groups, as it draws attention away from their needs and misstates the essential objectives of education. This paradigm has failed to raise the awareness of Governments and financial organizations and has resulted in delays or refusals to modify public policies that validate and perpetuate discrimination.

28. Therefore, educational systems must change and move beyond the paradigm of considering education as an expense that promotes macroeconomic development and perpetuates the essentially discriminatory socio-economic environment. This reveals the failure of some educational reforms, where it was hoped that education would alleviate social and economic problems that Governments could not resolve directly.

29. While access to learning is a vital component of the right to education, on its own it is no indicator of quality, effectiveness or ultimate purpose. Promoting high-quality education based on the study, experience and daily practice of human rights is essential to the construction of a society free of all forms of prejudice, exclusion and discrimination.[14] Moreover, learning is a process that encompasses the lifespan of every individual and thus must be seen as a lifelong experience. It is also essential that this lifelong process moves closer to human rights in order to help move individuals and societies towards the realization of a human rights culture.

B. Concept of lifelong learning

30. The notions that lie at the heart of lifelong learning have a long history. Plato (427-348 B.C.) already indicated that education and learning are not restricted to formal institutions. Other cultures have been described as witnessing comparable

[12] Lagarde y de los Ríos, M., *Los cautiverios de las mujeres: madresposas, monjas, putas, presas y locas*, Universidad Nacional Autónoma de México.

[13] Bourdieu, P., *La domination masculine*, Editions du Seuil, Paris, 1999.

[14] See E/CN.4/2005/50.

discourses on lifelong learning, the origins of which can be traced to their own traditions and the work of intellectuals, such as Confucius (551-479 B.C.).[15]

31. Nevertheless, the widespread acceptance and practice of lifelong learning remains a relatively recent phenomenon, which may be explained by considering the modern global context. This is characterized by economic uncertainty, international instability, technological advances, increased geographical mobility, increased population displacement and increased cultural diversity. Pervasive discrimination contributes to, and is found deep within, each of these characteristics. Our learning needs are inextricably linked with this changing environment.

32. The term lifelong learning is said to have been coined by adult educators. They wished to dispel the myth that most learning takes place "in two stages", namely primary and secondary, which may sometimes be extended by tertiary education.[16] Education is limited neither to the sphere of formal education, nor to the experiences of children and students.

33. Instead, learning must be recognized to be a lifelong experience. Many scholars argue that the largest part of learning occurs in an informal or non-formal setting, with formal education associated with the attainment of qualifications constituting a minor part of total learning.[17] Lifelong learning aims to improve individuals' knowledge, understanding, abilities and capabilities in all contexts, including personal, societal and professional.[18]

34. Three complementary terms are frequently used when considering different forms of learning activity, namely "formal", "informal" and "non-formal" education. Their exact definition varies according to the given context, which includes geographical, cultural and temporal considerations. Nevertheless, formal learning is generally described as being intentional, taking place in a formal setting and having clear learning objectives. Informal learning, in contrast, is unintentional and follows on from everyday experience. Non-formal learning may be understood as existing between those two extremes. It is intentional and fairly structured. However, the activity that results in non-formal learning may be neither intended nor traditionally described as being a learning activity.[19]

35. Several attempts have also been made to identify and list possible physical contexts for lifelong learning. Regular schooling on primary, secondary and tertiary levels can, for example, be supplemented by home schooling, adult education, continuing education, professional development, on-the-job training, literacy groups, study circles or self-directed learning.[20]

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[15] Aspin, D. N., Chapman, J., Hatton, M., and Sawano, Y. (eds.), *International Handbook of Lifelong Learning*, 2001, Springer, p. xvii.

[16] Traynor, G. J., *Lifelong Learning*, http://www.sydneycommunitycollege.com.au/p. 956.

[17] Aspin et al., 2001, op. cit.

[18] Commission of the European Communities, "Making a European Area of Lifelong Learning a Reality" (COM(2001) 678 final), Brussels, 21.11.2001, p. 10.

[19] Werquin, P., Recognition of non-formal and informal learning in OECD countries: A very good idea in jeopardy? *Lifelong Learning in Europe*, Vol. 3, 2008, p. 44.

[20] Aspin, D. N. and Chapman, J. D, Lifelong Learning Concepts and Conceptions, In D. N. Aspin (ed.), *Philosophical Perspectives on Lifelong Learning*, Springer, 2007.

C. Initiatives promoting lifelong learning

36. An understanding of the broad scope and possible implications of lifelong learning can be greatly illustrated by a consideration of practical examples. Action takes place on a national level, through, for example, the establishment of specific units and departments dedicated to lifelong learning. At the same time a number of intergovernmental bodies and organizations have either taken up the issue of lifelong learning or have been formed to further it. The following recent case studies aim to be illustrative but not all-inclusive.

37. In 2001, the European Commission adopted a communication entitled "Making a European area of lifelong learning a reality", which presented the European Union's understanding of lifelong learning and outlined its priorities for action.[21] The following year, the Council of the European Union passed a resolution that also treated lifelong learning. Those two documents, among others, stress that lifelong learning plays an important role in ensuring the employability of individuals, as well as the competitiveness of the European Union market as a whole. Furthermore, lifelong learning is viewed as contributing to social inclusion, active citizenship and personal development.[22] To assist member States in implementing the ideas contained within such documents, numerous educational and training initiatives have been integrated into the European Union Lifelong Learning Programme, which, in 2007, replaced previous education, vocational training and e-Learning programmes.[23]

38. The United Nations Educational, Scientific and Cultural Organization (UNESCO) has launched numerous initiatives related to lifelong learning. The Education for All movement, for example, began in 1990 and was renewed a decade later.[24] In 2003, UNESCO launched the United Nations Literacy Decade, which aims to reach both illiterate adults and out-of-school children.[25] Alongside such programmes stand more permanent structures; for instance, a series of International Conferences on Adult Education has been and continues to be organized.[26] Of perhaps the greatest significance, however, is the existence of the UNESCO Institute for Lifelong Learning, which is run as a non-profit institute and is one of six international UNESCO educational institutes. It conducts research and training,

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[21] Aspin et al., 2001, op. cit.

[22] Commission of the European Communities, *Adult learning: it is never too late to learn* (COM(2006) 614 final), Brussels, 23.10.2006, p. 2.

[23] Commission of the European Communities, *Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions: an updated strategic framework for European cooperation in education and training* (COM (2008) 865 final), Brussels, 16.12.2008; and Council of the European Union, *Draft 2008 joint progress report of the Council and the Commission on the implementation of the "Education & Training 2010" work programme "Delivering lifelong learning for knowledge, creativity and innovation" — Adoption* (5723/08 EDUC 29/SOC 46), Brussels, 31.01.2008. See http://ec.europa.eu/education/lifelong-learning-programme/doc78_en.htm.

[24] UNESCO, *EFA Global Monitoring Report, Overcoming Inequality: Why Governance Matters*; Oxford University Press, 2009. See also http://www.unesco.org/uil/en/focus/educforall.htm.

[25] UNESCO, *The Global Literary Challenge, A profile of youth and adult literacy at the mid-point of the United Nations Literacy Decade 2003-2012*, Paris, 2008. See also http://www.unesco.org/uil/en/focus/unliteracy.htm.

[26] UNESCO, http://www.unesco.org/en/confinteavi/.

collects information, documents observations and produces publications relating to literacy, non-formal education, adult and lifelong learning.[27]

39. A third example of intergovernmental action taken to further lifelong learning is offered by an organization called the Commonwealth of Learning. Created voluntarily by heads of Government of States belonging to the Commonwealth, the organization encourages the development and distribution of open learning as well as distance education. It does so through both country-specific and regional programmes and initiatives. In addition, the Commonwealth of Learning offers so-called "fee-for-service" consulting for international bodies and national Governments.[28]

40. On a national level, many universities have formal units dedicated to lifelong learning, while some Governments have set up specific departments. An example is the Academy of Lifelong Learning, which is located within the University of Delaware in the United States of America. Such academies promote lifelong learning among mature age students.[29] In the United Kingdom of Great Britain and Northern Ireland, the Scottish parliament has established a Lifelong Learning Department responsible for higher and further education.[30] Some Government initiatives do not necessarily need to exist as permanent Governmental institutions. Since 1996, Slovenia has been hosting an annual, national Lifelong Learning Week. Following year-long projects and preparations, the Lifelong Learning Week features around 4,000 different events related to learning, education and training.[31]

41. Furthermore, Governments may work together with civil society actors in establishing and implementing lifelong learning initiatives. On the African continent, literacy programmes often constitute a key first stage of basic adult education.[32] The Kenya Post-Literacy Programme is illustrative of a programme that was launched by a local non-governmental organization, but that later received Government support. The success of the Kenya Post-Literacy Programme in providing opportunities for Kenyans to continue learning after graduating from existing basic literacy programmes saw it not only expand from a regional to a national programme, but also receive full Government funding in 2002.[33]

42. Entirely community-based initiatives are also of importance, with the diversity in their nature reflecting the creativity of their initiators in attempts to best respond to the specificity of a given situation. Such initiatives may be local, regional, national or international in nature. A key example of a global, community-based lifelong learning initiative is that of the University of the Third Age, commonly known as "U3A". By "third age" this concept refers to persons that are no longer

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[27] UNESCO Institute for Lifelong Learning, *About UIL*. See http://www.unesco.org/uil/en/about/about.htm.

[28] Commonwealth of Learning, http://www.col.org/about/whatis/Pages/default.aspx.

[29] The Academy offers a wide variety of programmes; see University of Delaware, Academy of Lifelong Learning, http://www.academy.udel.edu/about/index.html.

[30] See "Life Through Learning; Learning Through Life Scotland: The Lifelong Learning Strategy for Scotland", published by the Scottish Executive, February 2003, http://www.scotland.gov.uk/Resource/Doc/47032/0028819.pdf.

[31] Slovenian Institute for Adult Education, *Lifelong Learning Week*. See http://llw.acs.si/.

[32] Aitchison, J. and Alidou, H., *The state and development of adult learning and education in Subsaharan Africa — Regional synthesis report*, UNESCO Institute for Lifelong Learning, Hamburg, Germany, 2009, p. 18.

[33] Slovenian Institute for Adult Education, op. cit.

part of the active workforce. The first U3A was started in Toulouse, France, in 1972 and the model has since spread across Europe, as well as to such countries as Australia, Costa Rica and South Africa. Around 40 such universities now form a loose network across the globe. Although frequently associated with a local, regular university, they remain community-based initiatives. U3As have been described as a setting in which "the teachers learn and the learners teach".[34] Such learning cooperatives benefit from the varied knowledge, previous experiences and specific skills of their members when designating their teachers.

43. Study circles, as another form of community initiative, consist of small groups of people who meet repeatedly and usually on a regular basis to discuss a subject or issue of their choice. The groups may choose to treat a common interest or to find solutions to a mutual problem. While this form of learning does not have a teacher, study circles often nominate a moderator to provide a structure of sorts and ensure that all members present get the most out of any one meeting.

IV. Human rights learning

44. Lifelong learning plays an important role in generating new solutions to adapt to a changing environment, as well as strengthening international teamwork and active citizenship at all levels of consequent action. Today more than ever, it is evident that Government policies and development processes must be reformulated to ensure that they are applied to the true aims of a quality education, that is, in such a way that they are geared ever more closely to the creation of universal opportunities and rights and full enjoyment of the achievements of humanity.

45. The Special Rapporteur therefore believes that there is a pressing need to extensively and critically rethink educational proposals at all levels of action. It is widely recognized that a well-educated population allows for a more productive workforce, as lifelong learning includes both further education and on-the-job training. However, it is important that investments in education and educational reforms are not made based upon purely utilitarian considerations.

46. A commitment to present and future generations is needed, as well as a careful direction of learning processes and entire learning environments and infrastructure. Such developments form part of the lifelong learning approach. The advancement of knowledge, abilities and skills within a political body primed to respect dignity and the higher values of humanity, diversity, peace, solidarity and mutual cooperation should be aimed at. Moreover, the Special Rapporteur views lifelong learning without consideration of the rights of all, and especially without human rights learning, as standing in contradiction with the human rights obligations of States.

A. Concept of human rights learning

47. The United Nations has been particularly active in specifying educational objectives for member States, including those concerning human rights learning. The Charter of the United Nations (1945) calls for cooperation "in promoting and encouraging respect for human rights and fundamental freedoms" (Art. 1(3)).

[34] The Third Age Trust, http://www.u3a.org.uk/index.php?option=com_content&task=category&sectionid=4&id=16&Itemid=52.

Similarly, the Universal Declaration of Human Rights (1948) states that "[e]ducation shall be directed ... to the strengthening of respect for human rights and fundamental freedoms" (Art. 26(2)).

48. Numerous subsequent texts have reiterated these calls and have been accompanied by initiatives that aim to flesh out their actual meaning and content. Particularly noteworthy here is the declaration of the 1995-2004 United Nations Decade of Human Rights Education, which was seen as a unique strategy for the "building of a universal culture of human rights".[35] The declaration of the International Year of Human Rights Learning, beginning on 10 December 2008, further highlighted the importance assigned by the United Nations and the international community to human rights learning.[36]

49. In its resolution 49/184, the United Nations General Assembly outlined the basics of the notion of human rights learning or education by stating that it "should involve more than the provision of information and should constitute a comprehensive lifelong process by which people at all levels in development and in all strata of society learn respect for the dignity of others and the means and methods of ensuring that respect in all societies". In so doing, human rights education "contributes to a concept of development consistent with the dignity of women and men of all ages". The Special Rapporteur also welcomes the recent role of the Human Rights Council Advisory Committee, which is discussing a draft United Nations Declaration on human rights education and training.[37] The Special Rapporteur hopes that such a future Declaration may offer a comprehensive, clear definition of human rights education and might spell out education activities encompassing fundamental human rights principles, such as equality and non-discrimination.

50. When considering the notion of human rights education, the unfortunate divide that has taken place, in theory and in practice, concerning the meaning of "education" must also be addressed. For many, education means the type of prescribed curriculum delivered through public education that introduces the student to a standard set of measures and principles, which define the status quo. Acquiring such information can be useful in many instances, but it is hardly adequate for the lifelong learning that will move individuals and societies towards the realization of a human rights culture. To arrive at this goal, transformative education in which the individuals gain a deep and personal understanding of the meaning and relevance of human rights for themselves and for fellow human beings must occur.

51. World-renowned peace educator and human rights scholar, Betty Reardon, has explained the reasons why this educational process should be referred to as human rights learning, rather than human rights education, as follows:

> "The basic distinction between Human Rights Education and Human Rights Learning is between education and learning. The word 'education' has been co-opted by those who determine what is to be taught, to whom and how it is

[35] A/51/506/Add.1, appendix, para. 2.

[36] See General Assembly resolutions 62/171 and 63/173, and also Suarez, D. and Ramirez, F., "Human rights and citizenship: the emergence of human rights education", *CDDRL Working Papers, No. 12*, Center on Democracy, Development, and the Rule of Law, Stanford Institute for International Studies, Stanford, 2004, p. 42.

[37] See Human Rights Council resolution 6/10.

to be taught, not just by the schools, but any authority that has control over information. The purpose of education is usually to get people to believe what and think as the 'education authorities' want them to. Learning has not yet been so co-opted. Learning can still be what happens in those who are presented with ideas, issues, values, queries about problems, and through reflection, analysis, assessment and evaluation come to understand and hold independent ideas about their societies and as much of the world as they 'learn' about.

Education has become mainly input. If it has any authentic output it is learning. But mainly it is socialization to conformity and indoctrination in the dominant value system. Authentic learning happens in and at the will of the learner. Human Rights Learning is more consistent than human rights education with the fundamental purpose of human rights concepts and standards, making it possible for all persons to realize their full human dignity. It begins with assuming the rights of the learners to decide themselves what they will believe and develops means through which the learners can acquire information while forming their own opinions and determining their own course of action about the issues of concern to them. (There are still some places in which education is centred on learning, but few. Education at least provides basic information. For the reflective who can resist indoctrination, it can be the beginning of learning. And where people have none of the tools of acquiring information, it is better than nothing.)

However, in the absence of authentic Human Rights Learning people will not be able to achieve their full dignity. Education may provide information about human rights, but it will not necessarily enable learners to develop the capacity and the motivation to fully realize them."[38]

52. The most prominent feature of the mode of human rights learning explained above is the concept and practice of a transformative pedagogy of human rights, which holds the potential for altering the power structure behind most forms of inequities and oppression. This concept of transformative learning is similar to the "deep approach" to learning or active learning according to which the learner reaches a personal understanding of the material presented and interacts critically with the content, relating it to previous knowledge and experience, as well as examines evidence and evaluates the logical steps by which conclusion shave been reached. This concept also challenges the "surface approach" or the traditional teacher-centred approach.[39]

53. In more practical terms, human rights learning has also been defined as "a developing field and curricular movement"[40] that includes "training, dissemination,

[38] Reardon, Betty, in Koening, Shulamith, "The nature of human rights learning: For all to know human rights as a way of life". Speech delivered for the celebration of the sixtieth anniversary of the Universal Declaration of Human Rights, accessible at http://www.pdhre.org/shula-vienna.pdf.

[39] See Jones, R. and Scully, J. (1996) "Hypertext within Legal Education", 1996 (2) *The Journal of Information Law and Technology*, accessible at http://www2.warwick.ac.uk/fac/soc/law/elj/jilt/1996_2/jones/.

[40] Suarez and Ramirez, 2004, op. cit., p. 2.

and information efforts aimed at the building of a universal culture of human rights through the imparting of knowledge and skills and the moulding of attitudes".[41]

54. Human rights learning is a prerequisite of lifelong learning, but the opposite is equally true. The Special Rapporteur therefore deems lifelong learning and human rights learning to be inextricably linked and essential for every society. Furthermore, the Special Rapporteur stresses that human rights learning must involve education as a whole and not simply be applied to isolated parts of the curriculum in a formal learning context.

B. Initiatives promoting human rights learning

55. The Special Rapporteur has been informed of numerous concepts and initiatives that aim to further human rights learning, including those of civil society actors, international organizations and individual State Governments.

56. The People's Movement for Human Rights Learning has been the key promoter of the concept of human rights communities. The members of such a community, also referred to as a human rights city, include everyone "from ordinary citizens and community activists to policy-makers and local officials". What makes a city a human rights city is the fact that community members "pursue a community-wide dialogue and launch actions to improve the life and security of women, men and children based on human rights norms and standards".[42]

57. This process includes efforts to increase a community's awareness of actions that they can take to effectively realize the political, civil, economic, social and cultural rights that they are entitled to. The human rights cities initiative is therefore built upon the belief that the transformation of human rights norms and standards from paper into practice requires citizens to learn of and understand their human rights, and to do so throughout their lives. The precise method by which this human rights education takes place is dependent upon social, economic, historical and cultural specificities of a given community. It frequently features the establishment of a steering committee, which represents the key sectors of society, and which drafts a plan of action, monitors and evaluates its implementation and plays a leading role in assisting other communities in adopting similar models.[43]

58. An example of an international non-governmental organization that is active in the field of human rights learning is Human Rights Education Associates (HREA). This initiative supports human rights learning, trains both activists and professionals, conducts research and evaluation, develops educational material and programmes and assists community-building through online technologies. In doing so, HREA works together with individuals, Governments, non-governmental organizations and international organizations.[44]

59. The work of HREA includes the coordination of the Global Human Rights Education Network, which is involved in information and advocacy activities. It brings

[41] HR/PUB/Decade/1998/1.

[42] Marks, S. P. and Modrowski, K. A., *Human Rights Cities — Civic Engagement for Societal Development*, People's Movement for Human Rights Learning, 2008, p. 45.

[43] Ibid., pp. 46-49.

[44] For more information, see Human Rights Education Associates, http://www.hrea.org/index.php?doc_id=97.

together organizations that are involved in education and training activities and which promote human rights learning. Such voluntary networks are able to promote and facilitate the sharing of information as well as best practices among their members. The simple fact that fundamental human rights shall apply to all people helps to highlight the value of such action in the field of human rights learning.

60. An additional example of how non-governmental organizations can work to further human rights learning, as an essential component of lifelong learning, is the HREA series of *Research in Human Rights Education Papers*. This series aims to both encourage and distribute the results of research and assessments conducted in the field of human rights learning. The papers are written for a target audience that includes practitioners, academics and financial supporters of the project alike.[45]

61. The wide-ranging work of individual States in the promotion of human rights learning can be shown by considering some examples from Central and Eastern Europe, which the Special Rapporteur views as being particularly illustrative. In cooperation with partners in the Netherlands and Denmark, the Government of Albania commissioned the drafting and nationwide distribution of activity books for primary school children, which introduce the concept of human rights. In Poland, special emphasis has been placed upon the use of the media in heightening public awareness of international human rights instruments. This was achieved, inter alia, through the development of a series of half-hour informative television programmes that were not only aired publicly but also made available in videocassette form to educational institutes and non-governmental organizations. Human rights learning has also been promoted through extra-curricular arts, in the context of teacher training courses and through youth campaigns in Romania, Slovakia and Slovenia, respectively.[46]

V. Conclusions and recommendations

62. **The Special Rapporteur believes that the irrefutable need for education should be interpreted as broadly as possible, and in this context, he has thought it essential to raise the issue of lifelong learning and human rights. Learning must be seen as a lifelong experience, as it is a process that is forever incomplete. Created by adult educators to heighten awareness of and understanding for their efforts, the term "lifelong learning" encompasses formal, informal and non-formal education. Initiatives launched to promote lifelong learning can be found at the national as well as international level, in both governmental and non-governmental sectors. The Special Rapporteur views efforts made by intergovernmental bodies, such as the European Union and the United Nations Educational, Scientific and Cultural Organization, to be particularly illustrative of the possible implications of lifelong learning. He also believes that great potential lies with community-based initiatives, of which Universities of the Third Age (U3As) and study circles are just two of the many examples described in the present report.**

[45] Tekeli, K., *Human Rights Training for Adults: What Twenty-Six Evaluation Studies Say About Design, Implementation and Follow-Up*, Research in Human Rights Education Papers, Human Rights Education Associates, August 2007.

[46] Tibbits, F., *Case Studies in Human Rights Education: Examples from Central and Eastern Europe*, Council of Europe/HREA, 1997.

63. However, the Special Rapporteur insists that lifelong learning needs to move closer to the context of human rights, as this is essential for progression to a society free from all forms of prejudice, exclusion and discrimination and the realization of a global human rights culture. The concept of human rights learning is mutually interdependent with that of lifelong learning. To help illustrate this interdependence, the Special Rapporteur drew upon concepts and initiatives concerning human rights learning that he has seen in practice and has been made aware of. These range from the internationally recognized notion of human rights cities, to the work of particular non-governmental organizations, to the efforts of particular States.

64. The Special Rapporteur calls upon the international community to rethink, in a critical manner, educational proposals at all levels of action. It is important that investments into education and educational reforms not be made based upon purely utilitarian considerations to allow for a more productive workforce, nor focus merely on job training. The Special Rapporteur believes that the higher values of humanity, diversity, peace, solidarity and mutual cooperation should be pursued through constant, lifelong advancement of knowledge, abilities and skills.

65. The Special Rapporteur encourages the initiatives presented, which encompass both human rights and lifelong learning, and calls upon Governments, international organizations, civil society actors and human rights activists to draw upon those examples in working towards the realization of a global human rights culture.

66. The Special Rapporteur recommends to Member States and civil society organizations that they diversify and deepen their community-based experiences of human rights learning, so that the experiences realized in connection with the World Programme on Human Rights Education also have their equivalent in other communities, which would make it possible to further extend the target audience. To this end, new participatory methodologies that can cover the processes of alphabetization, training and divulgation need to be designed. The interchange of community experiences has been shown to be a suitable mechanism for promoting the best practices of human rights learning.

67. The Special Rapporteur also calls upon Governments to develop more and better experiences that involve communities in the learning processes of human rights, so that those learning processes may also spill over and be reflected in the formal schooling system and in other informal educational activities. Adult education, in particular, should contain a strong emphasis on the learning of human rights, so as to enable adults to develop the capacity and motivation to fully realize human rights in their daily activities and interactions. This would allow them to realize and be conscious of the conditions of inequalities and injustices that surround them and that they sometimes unconsciously contribute to.

68. Finally, the Special Rapporteur recommends that national human rights institutions reinforce their own capacities with a vision that integrates human rights learning, so that, when dealing with specific complaints of human rights violations, those institutions also take the opportunity to raise awareness of the need to build a culture that encompasses human rights.